

MOVING ETHICS



State of the art of clinical ethics support
in the Netherlands

Linda Dauwerse

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MOVING ETHICS

The title of this dissertation, ‘Moving ethics’, has various connotations. These are reflected in the image on the cover, combining a turning globe, a heart, and flowers.

The globe indicates that topic of this dissertation is part of a worldwide field of study, and that the results are connected to previous international inquiries. It also refers to the main purpose of this dissertation; to gain insight in the current geography of Clinical Ethics Support (CES) in the Netherlands. A full picture of the situation in the Netherlands may provide a basis for international comparison and dialogue. In this sense, ‘moving ethics’ means that CES is a worldwide movement.

The heart marks the Netherlands, the focus of this study. The heart also refers to the issues at stake in CES, which are close to the heart of professionals and patients. The research aims to bring to light how Dutch healthcare institutions deal with ethical dilemmas and tensions, which are related to core values of healthcare practice. In this sense, ‘moving ethics’ indicates that ethics moves participants in health care.

The flowers symbolize the fact that CES aims at improving health care. Both this study and other studies on CES show that clinical ethics may provide an inspiration and a foundation for an ongoing investigation in good care.

The circling movement of the globe refers to the main conclusion of this dissertation: the inquiry into the essence of care is infinite and should be subject of dialogue and ethical reflection continuously. In this sense, ‘moving ethics’ refers to ethics as a dialogical enterprise, involving a continuous movement of ethical reflection on the quality of health care.

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Moving ethics

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Linda Marie-José Dauwerse

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promotoren: prof.dr. G.A.M. Widdershoven
prof.dr. T.A. Abma

copromotor: dr. B. Molewijk

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Chapter 1



Introduction

1. INTRODUCTION

Clinical ethics support (CES) has become prominent in health care over recent decades. Internationally, we have witnessed the rise of clinical ethics committees and clinical ethics experts such as ethics consultants, giving advice on concrete moral questions experienced by professionals. Recently, new kinds of ethics support have been introduced, focusing not on expert advice but on fostering reflection with and among professionals in practice. An example is moral case deliberation (MCD). The growing attention on different kinds of clinical ethics support gives rise to various questions. What kind of clinical ethics support is available in health care institutions? What kind of clinical ethics support is needed for dealing with current moral questions in health care? What are the goals of clinical ethics support according to those who are working in health care? In this thesis we will address these questions, focusing on the Dutch context.

In this introductory chapter we will first describe some general developments in health care which have also created new moral questions. Next we will give an overview of developments in the field of ethics which have influenced the route clinical ethics support has taken. Then, we will present an overview of previous studies into the international practice of CES. Consequently, we will describe the purpose, research questions and design of the studies that are presented in this thesis. The chapter ends with an outline of the thesis.

1.1 Developments in health care

In this paragraph we describe developments in patient population, health care professionals and organization of health care which have created new ethical challenges and moral questions in health care.

Patient population

In recent decades, the patient population is reported to have become increasingly fragile as a consequence of increased life expectancy and chronic diseases. Nowadays, about 20% of the Dutch population is 65+¹ and in 2011, 31,8% of the Dutch population is reported to have one or more chronic diseases.² Two out of three people, at retirement age, have had at least two chronic conditions.³ These developments lead to other treatment questions and increased the need to go beyond the medical model.

In terms of their health care patients have become more active and critical, and are increasingly seen as subjects who have valid knowledge.⁴ After the patient movement, fighting against paternalism and professional autonomy, nowadays patient rights have become duties (being a good patient). Whereas in the past patients were passive listeners who trusted their physician unconditionally, nowadays patients are active consumers, who search the Internet for information about their diagnosis and enter into discussion with their physician.

Health care professionals

Health care professionals have become more influential as a consequence of the development of medical knowledge and technology, which increases possibilities to affect the lives of people. Traditionally, the basic principle of health care professionals was to try and cure diseases and keep the patient alive as long as possible. Nowadays, limitations of treatment and cures have become more visible. Although technology makes it possible to extend people's lives it is questionable to what extent we should do everything possible to do so.⁵ Health care professionals increasingly work interdisciplinarily and collaboratively with people who do not have a background in the specific discipline (like patients and family members). This not only leads to collaboration, but also introduces moral questions as roles, (hierarchical) relations and multidisciplinary cooperation change. Traditionally, for example, nurses were the aids of physicians, while nowadays nurses have specialized expertise.⁶ It is unclear how health care institutions deal with ethical challenges, emerging from these role (and power) changes.

Organization of health care

The organization of health care has changed from informal care given in small groups towards professional care given in (bureaucratic) formal organizations, defined as "large secondary groups organized to achieve goals efficiently".⁷ Yet, in various health care institutions, the limitations of (bureaucratic) formal organizations are increasingly being recognized, leading to a search for alternative organizational forms characterized by self-management and humanization.^{8,9} Other health care institutions still focus on efficiency and continue to grow through mergers. Economization increases the number of ethical issues concerning costs of care.

Increasingly health care institutions are being confronted with moral challenges around questions such as compliance and integrity, trust and cooperation and corporate social responsibility.¹⁰ These cannot be externalized nor solved by vertical steering, technical innovation and SMART formulated project plans, but ask for involvement and inspiration.¹⁰ As a consequence health care institutions need to pay attention to moral involvement within the organization¹⁰ and to organizational identity, image and culture.¹¹

1.2 Developments in health care ethics

As mentioned above, societal developments led to new ethical challenges and moral questions. Health care organizations are increasingly aware that the moral dimension of care requires attention. Which kind of ethics is appropriate for the various moral questions that are inherently present in health care? Traditionally, academic ethics was hardly interested in concrete societal problems. The focus was on investigating the nature of morality, rather than on helping to solve concrete moral issues. As a response to the growing number of ethical problems in society, new forms of ethics came up, with new names, such as applied ethics and bioethics. In medical practice, clinical ethics developed, aiming at providing support for clinicians in dealing with concrete cases. The term clinical ethics support (CES) was

introduced, referring to various kinds of support for professionals in health care concerning ethical issues. Below we will give a brief overview of these developments.

Applied ethics

The applied turn in ethics concerns methodological movements in philosophy and ethics, away from philosophical theory towards analysis of ethical issues in practice.¹² Applied ethics is distinguished from normative ethics (which investigates what makes something good or bad, an act right or wrong or a trait virtuous or vicious), and from meta-ethics (which investigates the nature of moral statements). Applied ethics concerns the application of normative ethical theories to practical problems. It philosophically investigates moral standpoints concerning particular issues in private and public life that are matters of moral judgment. Within applied ethics, philosophical methods are used to identify the morally correct course of action in various fields of human action, like bioethics, environmental ethics and business ethics. Applied ethics often follow a deductive approach, in which a theoretical framework (such as utilitarianism, deontological, or virtue ethics) is used to analyze a case. The deductive model is also called the engineering model of applied ethics;¹³ this model of applied ethics assumes that 1) there is a body of knowledge that persons can be more or less knowledgeable about, 2) this knowledge becomes applied by deducting conclusions from theories in light of relevant empirical facts and 3) the deduction can and must be carried out in an impartial, neutral, and value-free fashion.^{13, 14} Alternatively, inductive approaches have been proposed, such as casuistry,¹⁵ in which the case is the starting point (and afterwards reflected on, using ethical theory).

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Bioethics

The term ‘bioethics’ was introduced in 1970.^{16, 17} Bioethics is part of, and fosters, the applied turn in philosophical ethics.¹⁷⁻¹⁹ Bioethics is more specific than applied ethics, in that it focuses on moral issues in health care practices.²⁰ The emphasis was on theoretical (or normative) research, focusing on justifying what ought to be done by professionals in health care.²¹ It developed as an interdisciplinary academic field, aimed at contributing to social debate and health care policy making. Since the 1990s, empirical research methods have become more common in bioethics. This implies a turn towards empirical ethics, in which empirical data on experiences and views of participants in practice (physicians, nurses, patients, family) are seen as relevant, in that they contain moral considerations which may serve as a source for moral reflection.^{17, 22}

Clinical ethics

Clinical ethics is a sub-domain of bioethics in which bio-ethicists focus on concrete ethical problems in clinical practice. Clinical ethics can be defined as ‘*the practical and engaged attention to a broad range of ethical problems engaged in the care of patients*’.¹² Recently, arguments for including organizational ethics in the field of clinical ethics have been proposed.²³

Clinical ethics support

Clinical ethics support is the specific sub-domain of clinical ethics focusing on providing *support* for health care professionals in order to deal with ethical issues. Examples of CES are clinical ethics committees, ethics consultation, and moral case deliberation. Ethics committees and consultants are organizational structures and functions; moral case deliberation is in the first instance an activity, which provides support to professionals; it can also be structurally embedded in the organization in the form of a moral deliberation project and as such take the form of an organizational structure and function. Clinical ethics support aims to improve the ethical quality of patient care in practice.^{24, 25} CES requires not only specific knowledge and skills with respect to clinical ethics topics as such, but in addition requires knowledge and skills about what kind of support and what kind of methods and structures for CES contribute best to the clinical ethics requests from health care professionals or health care institutions. In contrast to other sub-domains of bioethics, clinical ethics support is not only, and not primarily, the work of academic ethicists. Professionals in practice play an important role in ethics committees, often act as consultants, and are involved in organizing MCD. CES is more closely related to concrete practices in health care, and developed in close interaction with these practices. Thus, it shows a large variety, depending on contextual circumstances and interpretations of practitioners involved.

1.3 Previous international survey studies on clinical ethics support

In the following paragraphs we present empirical findings from previous international studies on CES from the USA, Canada, the UK, Norway and the Netherlands in particular (for a more detailed overview see table 1).

In the USA, ethics consultation is an important kind of CES.²⁶ It is defined as “a service provided by a committee, team, or individual to address the ethical issues involved in a specific, active clinical case.”²⁷ Fox²⁶ distinguishes the following ethics consultation models: individual consultation (an individual expert performs a consultation for a case at hand), small team model (a team of 2-6 people perform a consultation for a case at hand) and a full-committee model (on average 9 people perform a consultation for a case at hand). Although general ethical principles still play an important role in U.S. ethics consultation services, there have been important initiatives which facilitate a shift from rule-based approaches to value-based approaches.²⁶ Fox et al.²⁶ showed that most US hospitals have a small team model (68% have a small team model, 23% a full ethics committee and 9% an individual consultant).

In Canada, Gaudine et al.²⁷ showed in a survey that clinical ethics committees (CEC) in Canadian hospitals have evolved over the past 20 years from 18% in 1984 to 85% in 2008. They defined an ethics committee as: “any committee recognized as being primarily involved in ethical issues regarding patient care”.^{28, p. 133} In Canada CEC meetings have become more regularized and formalized over time and although CECs continue to be predominantly advisory in their nature, there was a shift in priority from advising on policy and procedures in 1984 to meeting ethics education needs and providing counseling and support in 2008.²⁸

Historically, in Europe, clinical ethics committees were the main kind of CES and also currently they play an important role. Internationally published survey data are available from the UK and Norway. In the UK ethics committees are the most prevalent kind of CES; half of them also provide case consultation.²⁹ In Norway, ethics committees were evaluated in 2004; the conclusion was that the committees function in many different ways, but most clinicians assessed them as useful.³⁰

In the Netherlands the prevalence of ethics committees increased from 25% in 1991³⁰ to 43% in 2001.³¹ In 1991 (research) ethics committees were more often available in hospitals (75%) than in care for people with an intellectual disability, mental health care and nursing homes (respectively 40%, 27% and 19%). No distinction was made between clinical ethics committees and research ethics committees. In 1991 the most important goals of Dutch ethics committees were 1) testing research proposals and protocols and 2) giving advice concerning concrete treatment problems (consultation) and assisting in the development of guidelines and procedures.³¹ Using the plan-do-check-act cycle (Deming), Van Dartel and colleagues³² made an inventory of the ethics policy of care institutions in 2001. Organizational care vision, core values and ethical policy were seen as key indicators for the 'plan-phase'; ethics policy was communicated in regular work meetings to employees in 73% of the participating health care institutions.³² Intranet and professional training programs were hardly used as communication platform for ethics. The development of ethics policy (such as care vision, codes of conduct and ethical protocols) was mainly organized top down, and external stakeholders like the health inspectorate or patient organizations were hardly involved. In this study the availability of CES was seen as a part of the 'do-phase'; 77% of the respondents indicated that there was enough space to discuss ethical issues and they used their manager and colleagues for this. Ethics committees were available in 43% of the participating institutions; their most important goals were policy making, organizing thematic meetings and giving advice.

Over the last decade moral case deliberation has been introduced in Dutch health care institutions.³³⁻³⁶ In an MCD, normative considerations of participants in practice concerning a specific case are investigated, using a structured method, with the help of a trained facilitator. The aim is to increase the insight in the participants' moral considerations and to broaden perspectives through exchange with others. Whereas the aim of ethics committees and ethics consultation is usually giving ethics advice from an expert point of view (often using principles and/or abstract reasoning), MCD aims at fostering a dialogue on moral questions and dilemmas of participants. So far, survey research on the prevalence of MCD is not available.

In summary, most surveys describe the use of clinical ethics committees or ethics consultants as the main kind of CES. MCD, which is increasingly receiving attention in the Netherlands, is not often addressed in surveys. Furthermore, within the existing surveys, little attention has been paid to what health care institutions themselves see as their needs and goals regarding possibilities for CES.

Table 1: Overview previous international survey research on CES

	Research aim & questions	Results/conclusion
Fox et al, 2007 (US)	<p>Aim: To describe the prevalence, practitioners and processes of ethics consultation in U.S. hospitals</p> <p>Research questions: 1) How prevalent is ethics consultation (ECS) in U.S. hospitals? 2) Who performs ethics consultation and what are the backgrounds & training of these individuals? 3) How do ECSs function? 4) Are the ownership, teaching role, and the number of beds related to the characteristics of the hospital's ECS?</p>	<ul style="list-style-type: none"> -Response: 87,4% (random sample of 600 US general hospitals, stratified by bed size) -The prevalence of ECS in US hospitals is high (81% have one) -Large hospitals (> 400 beds) more often have ECS than small hospitals -Considerable time & resources are invested in CES and there is variation in the number of man-hours spent (on average 4 hours on individual consultation, 7 hours small team model and 15 hours full committee work). -Small team model most commonly used kind of ECS and on average 4 individuals participate -Particularly clinicians (physicians and nurses) perform ECS, (compared with a small proportion of non-clinicians (philosophers and theologians). -Many people who perform ECS do not have specific education for such (59%) -ECS were quite consistent concerning the goals that were characterized as primary, that is: intervening to protect patient rights, diffusing real or imagined conflicts and affecting a change in patient care that improves quality
Gaudine et al., 2012 (Canada)	<p>Aim: to gain an understanding of how Canadian hospital CECs have evolved over the past 20 years</p> <p>No research questions reported</p>	<ul style="list-style-type: none"> -Response rate: 51% (included hospitals have over 100 beds, of which at least some are acute care) -The prevalence of CEC increased from 18% (1984) to 58% (1989) to 85% (2012) -The size and composition of CECs varies -Meetings have become more standardized & formalized -Nature of CECs is advisory & their focus is on education
Slowther et al., 2012 (UK)	<p>Aim: To describe the current provision of ethics support in the UK and its development since 2001</p> <p>No research questions reported</p>	<ul style="list-style-type: none"> -Response rate: 62%, majority situated in acute trusts -All CES included a CEC with only one also having a clinical ethicist -Lay members were present in 72% of responding CEC -Individual case consultation increased from 29% (2001) to 50% (2012) -Access to & involvement in the process of case consultation is less for lay members than for health professionals -There is wide variation in committee processes and levels of institutional support -Over half of the CECs have evaluation
Forde et al, 2011 (Norway)	<p>Aim: to learn how the national directives concerning the CECs have been followed by the local hospital trusts and to explore how the individual CECs in Norway function 6 years after the 2004 evaluation.</p> <p>No research questions reported</p>	<ul style="list-style-type: none"> -Response rate: 79.5% -Activity of Norwegian CECs is substantial and the activity increased (compared to 2004) -The CECs are multi-professional and use a systematic approach -Serious issues are involved -There is great variety in activities between CECs (not always case referral) -Including the patient perspective actively has not come very far but awareness has increased -Most lay members do not know there is a CEC

	Research aim & questions	Results/conclusion
Van Willigenburg et al., 1991 (Netherlands)	<p>Aim: To gain insight on the level and way Dutch health care institutions raise and deal with ethical and religious issues</p> <p>Research questions: -How do institutions deal with ethical and religious aspects of care-giving? -How can ethical and religious issues on the policy and management level be dealt with in a meaningful way?</p>	<p>-Response rate: 63.5% (n = 442)</p> <p>-(Top) management has attention for ethical and religious issues</p> <p>-60% of the respondents (N =) has an need for support from the institution</p> <p>-Most pressing moral questions are: privacy, waiting lists and responsibility towards personnel</p> <p>-25% have an ethics committee</p> <p>-Expected urgent moral issues in future are: scarcity and limitations to care</p> <p>-Religious views often are the base for moral choices, although the treatment of moral issues does not always concern a religious consideration</p> <p>-Ethical issues better suit management level than religious considerations</p> <p>-The prevalence of ethics committees increased</p> <p>-CECs have the following tasks: checking, consulting and protocols.</p> <p>-Medical staff meetings also function as advisory for directory concerning ethical issues</p> <p>-Role of (top) management is initiating and stimulating. In practice they often take the initiative for ethical problems and have a mediating role in the concrete dealing with ethical issues.</p>
Van Dartel et al., 2001 (Netherlands)	<p>Aim: To provide an actual overview of ethics policy in Dutch health care institutions</p> <p>What is the significance of ethical starting points and policy documents like core values, care visions and protocols? How important are they for management, how do they develop and how are they communicated? -What are the most important ethical issues of care management? -How do care institutions justify their ethics policy?</p>	<p>-Response rate: 12.8% (n= 289)</p> <p>-PDSA circle as basic framework</p> <p>-Ethics policy is an answer to societal developments and policy documents aim to give employees direction and show responsibilities of the organization</p> <p>-Cultural diversity of patients and tensions between free market policy against solidarity are challenges</p> <p>-98.5% of care workers asks for (informal) ethics support from their direct leader and direct colleagues</p> <p>-The management of ethics is more a line position than a staff position</p> <p>-43% of the Dutch health care institutions that responded have an ethics committee</p> <p>-Ethics committees have a short life span</p> <p>-Patients and care workers are the most important stakeholders of care institutions</p> <p>-Dutch care managers have well-developed interest in social accountability and this is expected to increase in the future (for example: 72% of the managers agree with the position that social accountability will be generally accepted within 5 years)</p>

2. PURPOSE AND RESEARCH QUESTIONS OF THIS THESIS

The primary purpose of this study was to give an overview of the current provision and characteristics of various kinds of Clinical Ethics Support (CES) in the Netherlands. The secondary purpose was to give an overview of the goals and needs of CES from the perspective of top managers and ethics support staff of health care institutions.

2.1 Research questions

The main research question was: How prevalent is CES and what are its characteristics in the Netherlands?

The sub questions were:

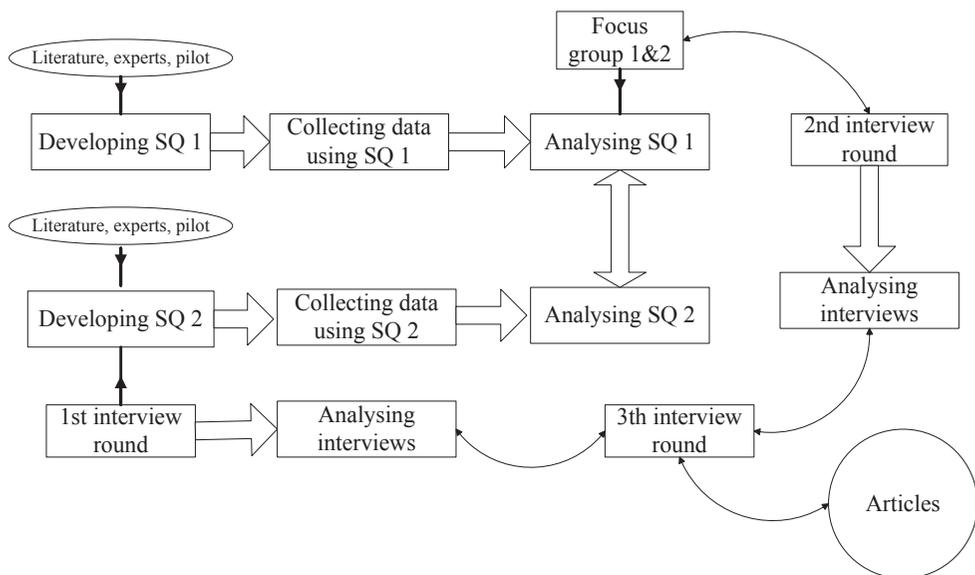
1. How prevalent is CES and what are its characteristics in the Netherlands?
2. What are the needs and goals of health care organizations concerning CES?

3. RESEARCH DESIGN

3.1 Mixed methods design

The study had a mixed methods design. Quantitative methods were used to provide an overview of the number of CES activities in Dutch health care institutions. Qualitative methods were used to interpret underlying considerations and evaluations of CES activities. The data collection process was cyclic and emergent (iterative), meaning that steps naturally evolved during the research process (see figure 1). During this process we were open to suggestions and needs of stakeholders and, for example, included implicit CES, which we had not anticipated. During the data analysis process, we compared and combined the findings of the various methods. Quantitative and qualitative methods were regarded as equally important. Different methods were used both sequentially and concurrently (see figure 1).

Figure 1: Research process



4. SETTING AND METHODS

In this section we describe the setting and the research steps.

4.1 Setting

The research setting consisted of all Dutch intramural health care institutions, registered by the Dutch Ministry of Health, Welfare and Sports in 2007. It included hospitals, mental health care institutions, nursing homes, care homes and care for people with an intellectual disability.

4.2 Infrastructure and sampling

In addition to the research team (consisting of four researchers), an advisory team was formed, including representatives of the four sectors (hospital, mental health care, elderly care and care for people with an intellectual disability) and a representative of the Ministry of Health, Welfare and Sports.

We approached all Dutch health care institutions (2137) in SQ 1. Meaning we did not use a sample. SQ 1 was addressed to managing directors of the health care institutions, aiming to get insight into their views and experiences. In SQ 1, we asked for names of ethics support staff members for follow up research (SQ 2). SQ 1 also enabled us to develop a national database of institutions and people interested in CES.

4.3 Data collection

In order to gather data on the current provision and characteristics of CES in the Netherlands, we developed two survey questionnaires: one for managing directors and one for ethics support staff. Managing directors included board members, directors and location managers and ethics support staff refers to employees of a health care institution who organize and implement ethics support (such as chairs of ethical committees, or spiritual caregivers). The underlying reason for these respondent groups was that they have a key role in facilitating (managing directors) and the actual organization and implementation of CES (ethics support staff). These two questionnaires were developed in close connection to the field (for SQ 1, seven expert conversations were used for SQ 2 we used twelve expert conversations) and tested with pilots (SQ 1 was tested on nine respondents from the target group; SQ 2 on 12 respondents). SQ 1 provided a base for SQ 2 (sequentially) and also investigated the same phenomena at the same time (concurrently).

We organized individual interviews (N = 17) and two focus groups (both 11 participants) to collect in depth information about the provision and characteristics of CES in Dutch health care institutions and to exchange and have dialogue about experiences with (needs, goals and various kinds of) CES. SQ 1 provided the base for the focus groups (sequentially) and SQ 2 and the focus groups were timed in the same period (concurrently). The first interview round was also organized to understand and interpret SQ 1 as to develop SQ 2 (sequentially). Interview round 2 was organized after the focus groups in order to collect in depth insight in the development of CES in specific contexts (sequentially, convergent).

The third interview round was organized as end point of data collection and aimed at placing the findings in a broader (international) context (sequential, divergent).

4.4 Data analysis

Data analysis was an open and inductive process in which we intentionally moved between diverse methods and data sets. Inductive means that we started with (specific) data and not with a (general) theoretical framework. Only after data analysis we turned to theoretical frameworks and insights from literature, in order to deepen the findings. At the end of the research process, we compared the results to more global theories (see chapter 7). These theories were not used in the primary analysis.

The analysis started with a large amount of data, collected with SQ 1. This questionnaire consisted of closed and open questions and the results were analyzed using quantitative and qualitative methods. SPSS 15 and Excel were used to analyze the responses to the closed questions; responses to the open questions were explored through content analysis to identify common themes and key issues. Quantitative and qualitative data were compared and discussed within the research team. Throughout this process, emerging patterns and hypotheses were developed and checked, resulting in a refinement of the analyses. To confirm the analyses, individual member checks with interviewees and focus group participants were performed.

After the first (content) analysis of this first questionnaire the researcher conducted five interviews in which issues coming up in the first analysis of SQ 1 were addressed. The interviews took roughly 1.5 hours and were recorded, following approval. The interview reports were sent to the respondents for member check. After the five interviews we returned to the data and re-read the open ended questions and adapted the codes of the numeric data to the new insights from the interviews. The results of this second (thematic) analysis round were 1) used for questionnaire items in SQ 2 and 2) presented in two focus groups. For example, the qualitative data concerning goals and informal kinds of CES from SQ 1 were transformed to quantitative items in SQ 2. The focus group reports were sent to the respondents for member checks and feedback was integrated in the report. The reports of the two separate focus groups were integrated as part of the analysis of major topics, such as goals and needs related to CES.

After the focus groups four interviews were organized, including representatives of respectively ethics committee, moral case deliberation, ethics consultant and implicit kind of ethics support. Again, these interviews took roughly 1.5 hours, were recorded, following approval and the interview reports were sent to the respondents for member checks.

The closed questions of the second questionnaire were analyzed using SPSS 15, 20 and Excel and again, the open questions were explored through content analysis to identify common themes and key issues. They were compared with the previous analyzes (of SQ 1, the interviews and focus groups) and discussed in the research team. Finally, we conducted eight additional interviews to further understand our findings, for example by comparing them with the experiences of pioneers of ethics support from the UK, US and Germany. All respondent members checked the summary and we compared the emerging issues with analyses of the previous research steps.

5. QUALITY PROCEDURES

Criteria to assess the quality of mixed methods are still under development. Greene³⁶ argues for a mixed methods way of thinking. This involves openness to multiple ways of seeing and hearing, multiple ways of making sense of the social world and multiple standpoints on what is important and to be valued and cherished.³⁵ In order to assess the *quality of method* she proposes to adhere to quality criteria of the tradition in which the method is being implemented, and to warrant the *quality of the inferences* made she proposes to adopt a multiplistic stance which she describes as follows:

“My ideas about warranting the quality of the inferences in mixed methods inquiry feature the adoption of a multiplistic stance that (1) focuses on the available data support for the inferences, using data of multiple and diverse kinds, (2) could include criteria or stances from different methodological traditions, (3) considers warrants for inquiry inferences a matter of persuasive argument, in addition to a matter of fulfilling established criteria and (4) attends to the nature and extent of the better understanding that is reached with this mixed methods design, as that is the overall aim of mixed methods inquiry.” (Greene, 2007, page 169)

Mertens (2010)³⁷ formulates eight questions to assess the quality of mixed methods research (see table 2). According to her, quality includes adequately connecting research purposes and questions to methods and making explicit dilemmas emerging in the research process.

Table 2: Quality of mixed methods research

Questions to be asked in order to assess the quality of mixed methods studies
1. What are the multiple purposes & questions that justify the use of a mixed methods design?
2. Has the researcher matched the purposes and questions to appropriate methods?
3. To what extent has the researcher adhered to the criteria that define quality for the quantitative portion of the study?
4. To what extent has the researcher adhered to the criteria that define quality for the qualitative portion of the study?
5. How has the researcher addressed the tensions between potentially conflicting demands of paradigms in the design and implementation of the study?
6. Has the researcher appropriately acknowledged the limitations associated with the data that were collected to supplement the main data collection of the study?
7. How has the researcher integrated the results from the mixed methods? If necessary, how has the researcher explained conflicting findings that resulted from the different methods?
8. What evidence is there that the researcher developed the design responsive to the practical and cultural needs of specific sub groups on the basis of such dimensions as disability, culture, language, reading levels, gender, class and race?

*Table 10.2 Mertens, 2010³⁷

Mertens' questions are based on issues and concerns arising from previous mixed methods research. During the research process, we have kept the issues which are addressed in the questions in mind. We for example have reflected on the justification of using various methods, recognizing that we on the one hand aimed for an overview of the prevalence of clinical ethics support in the Netherlands, and of needs and goals, which requires quantitative methods, and on the other hand wanted to understand more in depth these findings, which calls for qualitative methods (question 1 and 2). We critically assessed the quality of our research by adhering to the criteria of validity and reliability in quantitative research and credibility and reliability in qualitative research (question 3 and 4). We tried to take into account the specific demands of various paradigms, working, for example, inductively in sampling for the interviews, selecting respondents purposively, which would not be in line with the criteria for a quantitative sample that needs to be larger and randomly selected³⁷ (question 5). We also reflected on the dependency of one source of data on another source,³⁸ which might lead to limitations (question 6). For example, we were aware that the focus group data cannot stand alone from survey questionnaire 1, as this questionnaire was used as a base for the focus groups. We also reflected on conflicts between qualitative and quantitative data (question 7). Finally, both in preparing the surveys, and the interviews and the focus groups, we were sure to be sensitive to the culture of the respondents, by having experts checking our questions, and using pilots (in the surveys) (question 8). In the discussion (Chapter 8), we will reflect on our methods and answer the questions formulated by Mertens (2010).

Outline of the thesis

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This thesis is divided in two parts. In the first part (Chapters 2, 3) we provide a general description of the prevalence and state of the art of CES in the Netherlands with extra attention for (the positioning of) MCD. In the second part we go into the goals (Chapter 4) and needs (Chapter 5) which managing directors and professionals, responsible for organizing ethics support in health care institutions, attribute to CES in Dutch health care. Furthermore, we give a focused description of the CES needs in elderly care (Chapter 6).

Part 1

In Chapter 2 we give an overview of the presence of explicit and implicit CES in Dutch health care institutions settings. A variety of contexts is included: hospital care, mental health care, elderly care and care for people with an intellectual disability. Within this chapter we reflect on combining various kinds of CES, both explicit and implicit.

In Chapter 3 we give a description of health care institutions with MCD (compared to institutions without MCD) and describe the characteristics of MCD within institutions having this kind of CES. We also provide information about the positioning of MCD.

Part 2

In Chapter 4 we present the needs of Dutch health care institutions related to CES. We investigate the need for ethics support of Dutch health care institutions and relevant factors to explain and understand the presence or absence of such need.

In Chapter 5 we describe the goals of CES as identified by board members and ethics support staff. We will present a framework in which the four clusters of main goals and their sub goals are visualized and analyze these against Caluwe & Vermaak's typology of organizations.

In Chapter 6 we describe specific characteristics and needs concerning CES in elderly care. We explore kinds of CES which are tailored to the often mundane and easily overlooked moral issues that arise in long-term care and discuss how CES could be connected to learning styles of practitioners in elderly care.

In Chapter 7 we integrate the findings of the chapters and answer the research questions by summarizing and discussing our main findings. We also reflect on methodological issues and provide recommendations for further CES research and CES practice.

REFERENCES

1. Portrait F, Lindeboom M, Deeg D. Health and mortality of the elderly: the grade of membership method, classification and determination. *Health Econ.* 1999; 8: 441–457.
2. Nationaal Kompas Volksgezondheid, versie 4.13, 26 sept 2013, RIVM, Bilthoven. www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/chronische-ziekten-en-multimorbiditeit/hoeveel-mensen-hebben-een-of-meer-chronische-ziekten.
3. European Union. European Union Health Policy Forum. Answer to DG SANCO consultation on chronic diseases, 2012.
4. Schipper K. Patient participation and knowledge. VU University Press, 2011.
5. Widdershoven G. Ethiek in de kliniek. Hedendaagse benaderingen in de gezondheidsethiek, 2000.
6. Moser A. Competency in shaping one's life. Autonomy of older adults with type 2 diabetes mellitus who are treated in a nurse-led clinic. *Datawyse*, 2009
7. Macionis, J.J. & Plummer, K. (2005) "Groups, organizations and the rise of the network society." In Macionis, J.J. & Plummer, K, *Sociology, a global introduction*.
8. Visse M. Openings for humanization in modern health care practices. 2012.
9. Kunneman H. Het belang van moreel kapitaal in zorg en welzijn. Publicatie bij Paul Cremerslezing, 2012.
10. Van Riel CBM. Identiteit en Imago. Recente Inzichten In Corporate Communication - Theorie En Praktijk. Academic Service, 2010.
11. Agich G. Clinical ethics as a practice. *Journal International de Bioéthique* 2009; 4 (20): 15-24.
12. Caplan A. Mechanics on duty: the limitations of a technical definition of moral expertise for work in applied ethics. *Can. J. Philos.* 8, 8, 1982.
13. Agich G. Clinical ethics: a role theoretic look. *Soc. Sci. Med.* 1990;30(4): 389-399
14. Jonsen AR, Toulman S. The abuse of casuistry, a history of moral reasoning. The Regents of the University of California, 1988.
15. Doucet H. Ethical deliberation in multiprofessional health care teams. Ottawa: University of Ottawa Press, 2001.
16. Borry P, Schotmans P, Dierickx K. The birth of the empirical turn in bioethics. *Bioethics* 2005; 19(1): 49-71.
17. De Vries M, Van Leeuwen E. Reflective equilibrium and empirical data: third person moral experiences in empirical medical ethics. *Bioethics* 2011; 9: 490-498
18. Borry P, Schotmans P, Dierickx K. What is the role of empirical research in bioethical reflection and decision-making? An ethical analysis. *Medicine, Health Care and Philosophy* 2004; 7: 41–53.
19. Abma TA, Baur VE, Molewijk B, Widdershoven GAM. Inter-ethics: towards an interactive and interdependent bioethics. *Bioethics*; 24(5): 242-255.
20. Sugerman J, Pearlman RA, Taylor HA. Empirical Approaches to Health Care Ethics. In principles of health care ethics, 2007.
21. Widdershoven G, Abma T, Molewijk B. Empirical ethics as a dialogical practice. Oxford Blackwell Publishing. *Bioethics* 2009;23(4):236-48.

22. Frith L. The NHS and market forces in health care: the need for organizational ethics. *J Med Ethics* 2013;39:17–21.
23. Slowther, A. (2008) Embedding clinical ethics in a health care system: the experience of the UK clinical ethics network. *Bioethica Forum*, 1 (1), 40–44.
24. McClimans LM, Dunn M, Slowther A. Health policy, patient-centred care and clinical ethics. *Journal of Evaluation in Clinical Practice*, 2007;17:913–919
25. Fox E, Myers S, Pearlman R. Ethics consultation in United States Hospitals: a national survey. *Am J Bioeth* 2007;7:13e25.
26. Tulsy JA, Fox E. Evaluating ethics consultation: Framing the questions. *Journal of Clinical Ethics* 1996;7: 109–115.
27. Gaudine A, Thorne L, LeFort SM, Lamb M. Evolution of hospital clinical ethics committees in Canada. *J Med Ethics* 2010;36:132-137.
28. Slowther AM, McClimans, L Price, C. Development of clinical ethics services in the UK: a national survey. *J Med Ethics*; 2012; 38: 210-214.
29. Forde R, Pedersen R. Clinical Ethics Committees in Norway: What Do They Do, and Does it Make a Difference? Special Section: Bioethics beyond borders. *Camb Q Health Ethics*, 2011; 20:389-95
30. Willigenburg van T, Verweij M, Kleemans CHM, Kloot-Meijburg van der HH. Ethiek, levensbeschouwing en het management in instellingen voor intramurale gezondheidszorg. Nationaal Ziekenhuisinstituut, 1991, Utrecht; 109-110.
31. Van Dartel JN van, Jacobs M, Jeurissen RJM. Ethiek bedrijven in de zorg. Een zaak van het management. 2002 Gorcum bv, Assen.
32. Manschot H, van Dartel H. In gesprek over goede zorg. Overlegmethoden voor ethiek in de praktijk. Boom, 2003.
33. Molewijk AC, Abma T, Stolper M, Widdershoven G. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *J Med Ethics*. 2008a;34(2):120-4
34. Molewijk, B Verkerk M, Milius H, Widdershoven G. Implementing moral case deliberation in a psychiatric hospital: process and outcome. *Med Health Care Philos*. 2008b;11(1):43-56.
35. Molewijk B, Zadelhoff E, Lendemeijer B, Widdershoven G. Implementing moral case deliberation in Dutch health care: improving moral competency of professionals and quality of care. *Bioethica Forum*, 2008c;1(1): 57-65.
36. Greene JC. *Mixed Methods in Social Inquiry*. San Francisco: Wiley & Sons, 2007.
37. Mertens DM. *Research and evaluation in Education and Psychology. Integrating Diversity with quantitative, qualitative and mixed methods*. Thousand Oaks, California: Sage publications, 2010.
38. Morse JM. Principles of mixed- and multiple-method research design. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 189-208). Thousand Oaks, CA: Sage.

Chapter 2



Implicit and explicit ethics support in the Netherlands. A mixed methods overview study

L. Dauwerse, F. Weidema, T.A. Abma, B. Molewijk, G. Widdershoven.
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ABSTRACT

Internationally, the prevalence of clinical ethics support (CES) in health care has increased over the years. Previous research on CES focused primarily on ethics committees and ethics consultation, mostly within the context of hospital care. The purpose of this article is to investigate the prevalence of different kinds of CES in various Dutch health care domains, including hospital care, mental health care, elderly care and care for people with an intellectual disability.

A mixed methods design was used including two survey questionnaires, sent to all health care institutions, two focus groups and 17 interviews with managing directors or ethics support staff. The findings demonstrate that the presence of ethics committees is relatively high, especially in hospitals. Moral case deliberation (MCD) is available in about half of all Dutch health care institutions, and in two third of the mental health care institutions. Ethics consultants are not very prominent.

A distinction is made between explicit CES forms, in which the ethical dimension of care is structurally and professionally addressed and implicit CES forms, in which ethical issues are handled indirectly and in an organic way. Explicit CES forms often go together with implicit forms of CES. MCD might function as a bridge between the two. We conclude that explicit and implicit CES are both relevant for clinical ethics in health care. We recommend research regarding how to combine them in an appropriate way.

Key words: Clinical ethics, Ethics committees, Ethics consultation, Institutional ethics, Bioethics, Moral case deliberation.

INTRODUCTION

Since 1970, clinical ethics support (CES) has developed both in the US and in Europe. In the context of hospitals, CES has largely increased over the years. In the last decades the prevalence of ethics consultation services in US hospitals grew from approximately 1% in 1983 (Youngner et al. 1983) to 100% of hospitals of 400 beds or more in 2007 (Fox et al. 2007). In Europe, clinical ethics support in hospital settings is also growing (Slowther 2007; Slowther et al. 2004; Reiter-Theil et al. 2011). In the UK, the presence of ethics committees in hospitals increased from 4.5% (20/456) in 2001 (Slowther et al. 2001) to 100% in 2012 (Slowther et al. 2012). In Germany the presence of ethics committees in hospitals has increased from 4% (30/795) in 2000 to 31% (149 / 483) in 2007 (Dorries 2007). In Norway the first ethics committees were established in 1996; nowadays (2011) all hospital trusts (n = 23) have an ethics committee (Forde & Pedersen 2011). In the Netherlands an increase of ethics committees in hospitals is also visible; from 75% in 1991 (van Willigenburg et al. 1991) to 89% in 2002 (van Dartel et al. 2002).

In the context of elderly care, ethics committees have also been introduced over the past years (Cox & Roy 1985; Brown et al. 1987; Aroskar 1987). In addition, other forms of ethics support have been developed, especially those with a focus on ‘everyday ethics’ (Bolmsjo et al. 2006, van der Dam et al. 2011ab; Horner & Kelly 2007; Browning 2011; van der Dam et al, 2013) and on the quality of the relationship with clients in assisted living facilities (Powers 2005). The same applies for various kinds of ethics support in mental health care and care for people with an intellectual disability (Greenfield & Jensen 2010; Roberts 2004; Weidema et al. 2013).

Over the past years, various kinds of CES have been developed. Ethics support within health care institutions not only includes ethics committees and ethics consultation, but also moral case deliberation (MCD) and ethics rounds (Molewijk et al. 2008; Svantesson et al. 2008). Other CES activities or CES products are for example ethics education, written documents and policies and ethical frameworks such as codes of conduct and protocols to assist professionals in dealing with and solving ethical problems (van der Dam et al. 2013).

Studies on CES in health care often focus on one setting (hospital care, elderly care, mental health care, care for people with an intellectual disability). The subject is mostly one or two kinds of CES, such as ethics committees and ethics consultation (Fox et al. 2007; Slowther et al. 2001&2012; Forde & Pedersen 2011). The aim of the present study is to provide an overview of various kinds of CES in various health care settings. We not only focus on instances of CES which have a formal position within the institution and provide professional guidance on a structural basis, like an ethics committee or ethics consultant. Next to these kinds of CES, which we call *explicit* CES, we distinguish *implicit* CES, which refers to situations in which ethics support is not structurally organized and ethical issues are not explicitly put on the agenda. Examples are (team) meetings, spontaneous conversations, and educational or policy settings which are not primarily focusing on ethics. Interaction with individual functionaries in the organization (such as spiritual caregivers) can provide as a form of implicit CES. Research on the presence and functioning of implicit CES has not been reported earlier.

In this paper we describe the prevalence of explicit and implicit CES in hospital care, mental healthcare, elderly care and care for people with an intellectual disability in the Netherlands. We will also go into the value of various kinds of CES as experienced by managing directors and professionals responsible for organizing CES. Finally, we will reflect on how to combine various kinds of, explicit and implicit, CES.

METHODS

By post, we asked managing directors of all (i.e. 2147) Dutch health care institutions (hospitals, mental health care institutions, elderly care institutions, and institutions for people with an intellectual disability) to participate in a national survey questionnaire. Managing directors included board members, directors and location managers. Respondents were also asked to provide contact information of ethics support staff within their institution, if present, for a second national survey questionnaire (web-based). Ethics support staff are employees who organize ethics support, for example ethics committee chairs. Data input was also sought from a wider stakeholder constituency, using interviews and focus groups. Participants were representative for the wide variation of domains in healthcare and functionaries involved in CES (including staff employees, managers and bioethicists).

Survey 1

The first survey took place between December 2007 and December 2009. This phase started by developing and designing a postal questionnaire in close connection with experts in the field of CES (n = 7). The questionnaire was tested with 9 participants. Considerable refinements were made to the survey tool (particularly to the length) and its introductory explanation. We sent two reminders. The main focus was on explicit ethics support (ethics committees, moral case deliberation and ethics consultation), but we also added the option 'other kinds of ethics support' in the questionnaire SQ1. This provided data on implicit ethics support.

Interviews and focus groups

Following the first survey (Sept 2008), the first author conducted five interviews with managing directors and ethics support staff to complement and get further insight in the data of the findings of the first questionnaire. In addition, two focus groups with 22 managing directors and ethics support staff members were organized in June and July 2009 in order to complement and finalize the results of the first survey. In these focus groups advantages and disadvantages of explicit and implicit ethics support were discussed.

Survey 2

The second survey took place between September 2008 and September 2010. A digital questionnaire was developed, based on interviews and (email) discussions with experts (n = 12). The questionnaire was designed via a web-based, flexible and secure survey development tool (enqueteviainternet.nl). It was pre-tested with 12 participants. The content of several

questions of the second questionnaire was already tested in the pilot of questionnaire 1, which further supported the face and content validity of the questionnaire.

The second questionnaire included sections on explicit and implicit ethics support. The options concerning implicit ethics support were based on the analysis of the results on implicit ethics support in questionnaire 1 (see table 1). We sent the second questionnaire to the ethics support staff members who were mentioned by the respondents of questionnaire 1. Two reminders were sent.

Interviews

After the second survey questionnaire, the first author conducted twelve individual interviews with ethics support staff members and managing directors from institutions with 1) an ethics committee, 2) moral case deliberation, 3) ethics consultation and 4) implicit kind of CES (peer-supervision). These interviews aimed to help interpret and reflect on the survey findings. The interviews focused on the experiences and views of interviewees concerning CES.

Table 1: Kinds of implicit CES, emerging from SQ 1

Category	Definition	Examples
Implicit individual consultation	Interaction with individual person concerning the ethical dimension of (everyday) care	Spiritual caregiver (e.g. pastoral or humanistic), trusts person, member of ethics committee, physician, psychologist, behavioral scientist, psychiatrist, external expert, informal caregivers, complaints functionary, staff employee. <i>'Physicians and spiritual caregivers play an informal role concerning ethical issues.'</i> <i>'(Un) asked advice from spiritual caregivers.'</i>
Group meetings	Existing work meetings in which ethical issues arise	Meeting (multidisciplinary, team, department, medical staff, management team, psychosocial caregivers, religious people). <i>'Each department has group conversations about moral questions'</i>
Policy / procedures	Existing policy/ procedures with an ethical dimension	Procedure for complaints, annual report, in quality standards, policy goals
Other committees	An organizational group who deals with ethical issues	Committee (medical ethical, value committee, education, identity, for professional attitude), council (for employees, clients, security, advice, nurses), department (ethics, philosophy and history, human resources), church
Education	Educational activities having attention for ethical dimension of care	Thematic session, in education of physicians and nurses (experience oriented care, own educational program on culture, values, norms)

Analysis

Both questionnaires consisted of closed and open questions; the results were analyzed using quantitative and qualitative methods. SPSS 15 and Excel were used to analyze the responses to the closed questions; responses to the open questions were explored through content analysis to identify common themes and key issues. Quantitative and qualitative

data were compared and discussed within the research team. Throughout this process, emerging patterns and hypotheses were developed and checked, resulting in a refinement of the analyses. To confirm the analyses, individual member checks with interviewees and focus groups participants were performed.

Interviews were transcribed. Initial coding was performed in line with quality criteria described in the literature, remaining open, staying close to the data and keeping codes simple and precise (Mertens, 2010). We constructed short codes, compared data, and involved team members in the coding when appropriate. We discussed differences in interpretation and use of the codes, revised codes if necessary and made a codebook that included brief descriptions of each code which facilitated a constant comparative method of analysis (Mertens, 2010).

The first and second author collaborated in the phase of focused coding. This required decisions about which initial codes made the most analytical sense to categorize the data incisively and completely. During the analysis, all authors discussed the categories until consensus was reached.

Response rate

During data collection it turned out that the initial 2137 individual health care institutions were members of 864 legal bodies (umbrella organizations with a legal status). As a consequence, there are two response rates for this first questionnaire, namely 30% (638 / 2137) at the individual institution level and 56% (485 / 864) at the legal body level. Respondents included board members, directors and location managers. In this article we refer to them as ‘managing directors’.

The (digital) SQ2 was sent by email to all the ethics support staff members (N = 515) designated by the respondents in questionnaire 1. The number of ethics support staff members was less than the number of respondents for questionnaire 1 (N=638) because not all respondents in questionnaire 1 designated an ethics support staff member. The response rate of the second survey questionnaire was 48% (247 / 515). Respondents included mainly ethics support staff such as spiritual caregivers, but in some cases also representatives from management.

RESULTS

In this paragraph we present data on the prevalence and perceived value of explicit and implicit CES in various Dutch healthcare contexts, as well as data on the prevalence and perceived value of combined explicit and implicit CES. For the prevalence, we used data from the second questionnaire, directed at ethics support staff. Ethics support staff report higher prevalence of CES than managing directors. We consider the data of ethics support staff more reliable, because they know more about CES in daily practice in the institution. For the perceived value, we used data from interviews and focus groups with managing directors as well as ethics support staff.

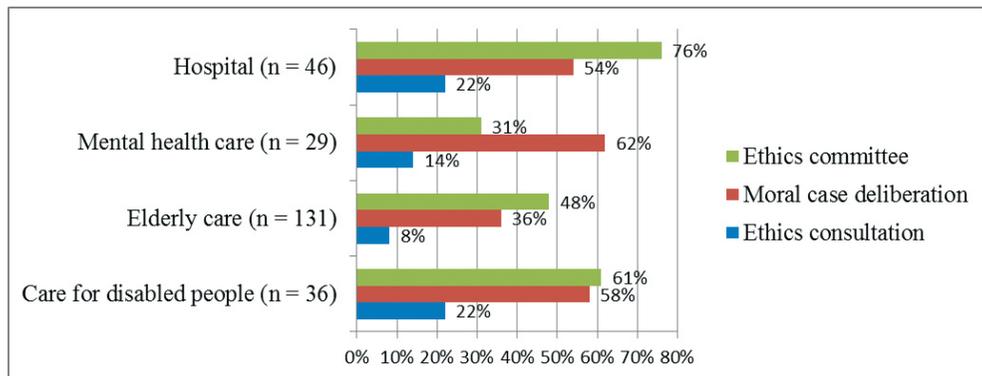
Explicit CES

Explicit CES concerns institutionalized structures with a formal role regarding ethical issues in health care. We found three kinds of explicit CES: ethics committee, ethics consultant, and MCD.

Prevalence in hospitals

Respondents from a majority (76%) of the surveyed Dutch hospitals report an ethics committee. In over half (54%) of the hospitals, moral case deliberation (MCD) is present (see figure 1). In one fifth (22%) of Dutch hospitals, an ethics consultant is mentioned. In almost half (46%) of the hospitals, an ethics committee is combined with MCD. In almost one fifth (17%), an ethics committee, MCD and an ethics consultant are available. Of respondents from the 11 hospitals without an ethics committee (24% of the total), 36% (4 hospitals) mention MCD and 9% (1 hospital) mention an ethics consultant (see table 2).

Figure 1: Explicit CES in Dutch healthcare institutions



Prevalence in mental health care

Respondents of two third (62%) of Dutch mental health care institutions report MCD is present in their institution. In one third (31%) an ethics committee is mentioned. In a small number (14%) of the Dutch mental health care institutions an ethics consultant is present. In almost one third (28%) of mental health care institutions, an ethics committee is combined with MCD, and in 7%, an ethics committee, MCD and an ethics consultant are present. From the 20 mental health care institutions without ethics committee (38%), in 50% MCD is available, and in 10% an ethics consultant (table 2).

Prevalence in elderly care

Respondents from almost half (48%) of the elderly care institutions report an ethics committee. In more than one third (36%), MCD is mentioned. A few (8%) Dutch elderly

care institutions have an ethics consultant. In almost one third (27%) of the elderly care institutions, an ethics committee is combined with MCD and in 5% all three are present (an ethics committee, MCD and an ethics consultant). From the 68 elderly care institutions without ethics committee, in 18% MCD is available, and in 6% an ethics consultant (table 2).

Table 2: Absence and presence of explicit CES

	Absence explicit CES		Presence explicit CES	
	N	%	N	%
Hospital care	6	13%	40	87%
Mental health care	10	35%	19	65%
Elderly care	52	40%	79	60%
Care people with intellectual disability	7	19%	29	81%

Prevalence in care for intellectually disabled people

In most Dutch institutions for people with an intellectual disability, an ethics committee (61%) or MCD (58%) is present. Ethics consultants are available in 22% of the institutions for people with a disability (figure 1). In two fifth (39%) of the institutions for people with an intellectual disability, an ethics committee and MCD are combined (table 2). From the 14 institutions without ethics committee, in 50% MCD is available, and in 7% an ethics consultant.

Table 3: Combinations of various kinds of explicit ethics support

	EC&MCD		EC & MCD & Cons		EC: yes, MCD: no		EC: no, MCD: yes		Total	
	N	%	N	%	N	%	N	%	n	%
Hospitals	21	46%	8	17%	14	30%	4	9%	46	100%
Mental healthcare	8	28%	2	7%	1	3%	10	35%	29	100%
Elderly care	35	27%	6	5%	28	21%	12	9%	131	100%
Care people with intellectual disability	14	39%	4	11%	8	22%	7	19%	36	100%

Comparing explicit CES in various contexts

Ethics committees are often available in hospitals (76%); in almost half of the participating hospitals an ethics committee is combined with MCD (while in the other contexts, this combination is present in one third).

In mental health care, MCD is more often present (62%) than an ethics committee (31%), while in the other contexts, this is the other way around. In elderly care the prevalence of MCD is lower (36%) than in other contexts, in which more than half of the participating institutions organizes MCD. In care for people with an intellectual disability, MCD (57%) is almost as prevalent as an ethics committee (60%) and, like in mental health care, MCD is relatively often used as an alternative for an ethics committee (in half of the institutions without ethics committees, MCD is present). In comparison with elderly care (8%) and mental health care (14%), the prevalence of ethics consultants is higher in hospitals and institutions for people with an intellectual disability (22%).

Experienced value of explicit CES

The interviews and focus groups with managing directors and professionals responsible for organizing CES indicate that explicit CES is valuable because it places ethical issues in health care explicitly on the agenda. Respondents emphasize that, from an organizational point of view, explicit CES is important because it creates connections in the organization, and guarantees continuous ethics support and systematic attention for the ethical dimension of care.

Respondents also indicate that the multidisciplinary character of MCD fosters an equal conversation between various disciplines (with different hierarchical status) about the ethical dimension of care:

“MCD realizes an equal ethics conversation between disciplines.” (People with an intellectual disability, spiritual caregiver)

Continuity implies that CES is offered on an ongoing basis, and that practitioners know where to find assistance in dealing with ethical issues. A respondent says:

“I attended a post graduate ethics course. Now, I am the functionary in our organization who knows about systematic proceeding ethical issues. In case of incidents, I am being consulted.” (Elderly care, spiritual caregiver).

Explicit CES makes that the ethical dimension of care is structurally on the agenda. Respondents explain that without explicit CES, attention for ethics is superficial:

“Other [not structural] ways of ethics support are often ad hoc, too much in a rush, and under pressure of finding a quick solution” (People with an intellectual disability, ethics support staff).

“Ethics is an intrinsic part of our daily routines; therefore ethics support should be organized in a structural way. If ethics support is organized only incidentally, a good foundation is missing. We do not want to invest in that.” (Hospital, managing director).

Implicit CES

Implicit CES concerns formal and informal structures in healthcare (like multidisciplinary team meetings and conversations with individual colleagues) in which the ethical dimension of care is addressed indirectly.

Prevalence in hospitals

Respondents from almost all (96%) hospitals report implicit CES (see table 4). Mostly (91%), they mention individual functionaries (such as spiritual caregivers) as a form of implicit CES (see figure 2). Almost three quarter (73%) of the respondents from the participating hospitals mention (i.e. non-ethics) committees, e.g. a quality management committee, as implicit CES. Furthermore, half of the respondents from hospitals mention other (i.e. non-ethics) kinds of education (55%), policy (55%) and group meetings (50%).

Table 4: Prevalence of implicit CES

Setting / Prevalence	Yes	Yes	No	No	Total	Total
	n	%	n	%	n	%
Hospital care	44	96%	2	4%	46	100%
Mental health care	28	97%	1	3%	29	100%
Elderly care	121	92%	10	8%	131	100%
Care people with intellectual disability	31	86%	5	14%	36	100%

Prevalence in mental health care

Almost all (97%) of the participating respondents from mental health care institutions mention implicit CES. Mostly (89%) this concerns group meetings like multidisciplinary team meetings. More than three quarter (80%) of the mental health care institutions report individuals providing implicit CES and more than two third (69%) other committees. Half of the Dutch mental health care institutions mention policy (54%) and/ or education (50%) as implicit CES.

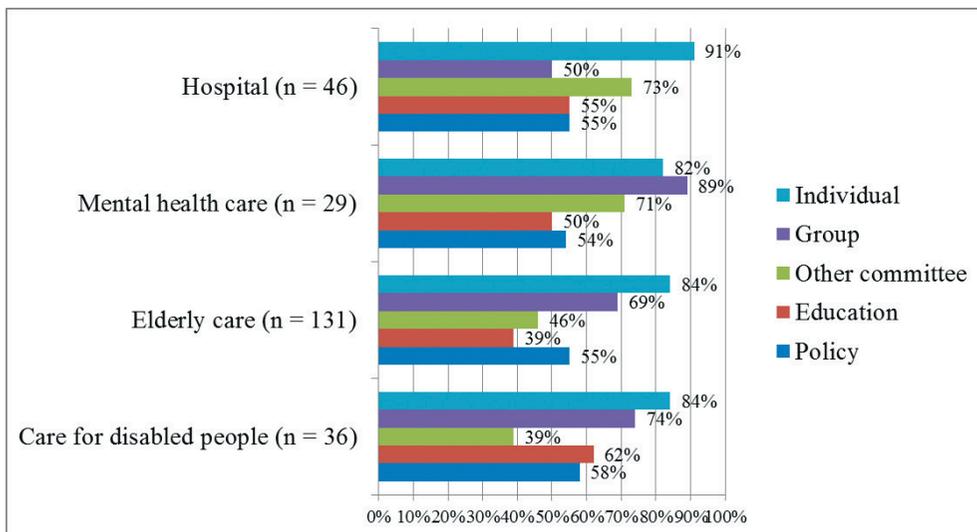
Prevalence in elderly care

Respondents from elderly care note that implicit forms of CES are often (91%) available. Mostly this concerns individuals (84%). More than one third (69%) of respondents mention group meetings and about half of the respondents mention policy (55%) and / or other committees (46%). Almost two fifth (39%) of the respondents mentions education (39%) as implicit kind of ethics support.

Prevalence in care for people with an intellectual disability

In institutions for people with an intellectual disability, many respondents (86%) mention implicit CES. The majority (73%) mentions individuals provide implicit CES. Almost three quarter (74%) of respondents mentions group meetings and approximately two third mentions education (62%) and / or policy (58%). Two fifth (39%) of respondents mentions other (i.e. non-ethics) committees.

Figure 2: Implicit CES in Dutch healthcare



Comparing implicit CES in various contexts

In all participating institutions, implicit ethics support is prominent. Especially individuals, like spiritual caregivers, are often mentioned as providing implicit CES (see figure 2). In mental health care, group meetings are more often mentioned as implicit CES than individuals. In the other contexts, this is the other way around.

Experienced value of implicit CES

Our findings from the focus groups and interviews indicate that the value of implicit CES is that it provides an open, organic and more narrative approach to the ethical dimension of care, which helps to evoke stories that might have been missed when ethics would be explicitly addressed:

“I talked with nurses about good care. They gave examples of what they assessed as good care. At the end I asked: ‘do you encounter ethical dilemmas in your work?’ They answered: ‘No, we are not really interested in ethics..’ I said: ‘I just talked with

you about ethics for 1,5 hour.' They were not aware of that." (senior staff member, centre of expertise for long-term care).

In implicit CES, ethical issues may rise spontaneously. Care workers do ethics 'on the fly', in the immediacy of their relations with individual and groups of clients, family and colleagues and this is seen as an important factor for continuous attentiveness to ethical issues. As a consequence, implicit CES provides a low-key way to pay attention to the moral dimension of everyday care and helps to prevent (often heavy-loaded) associations care workers have with the vocabulary and methods of ethics. A participant explains:

"Not everything fits moral case deliberation. A lot of what happens within institutions may not be openly qualified as ethical. Conversations or peer-supervision can have an ethical dimension." (Association for long-term care, staff member).

Combining explicit and implicit CES

Our qualitative findings indicate that institutions value explicit and implicit CES, and aim to foster both:

"It would be good to secure continuity of formal CES and guarantee the quality of informal CES." (Hospital, managing director).

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In several institutions, various forms of explicit CES are combined to integrally embed ethics in the organization. For example, MCD and an ethics committee are both available, and offered depending on the goal of the specific CES request: MCD addresses ethical issues on the shop floor, while an ethics committee deals with more general ethical issues in a formal group of experts. Other institutions combine various ways of explicit CES by changing the task of the ethics committee, and making the committee responsible for organizing and stimulating CES in daily practice:

"We transformed the ethics committee into an ethics steering group [organizing MCD in the organization]." (Hospital, medical ethicist).

Respondents, while recognizing the importance of implicit CES, stress the added value of explicit CES:

"Having conversations at the coffee-machine is fine, but some structure is also needed. One should learn to use a model to deal with ethical dilemmas." (Hospital, managing director).

On the other hand, respondents also acknowledge the added value of addressing ethical issues informally and spontaneously during individual contacts or group meetings:

“Structured peer-supervision provides an occasion to share problems that professionals come across. During these meetings people deliberate on the difficulties in their work. They reflect on their experiences. This implies an organic way of conversation in which often ethical issues are discussed.” (Mental health care, spiritual caregiver).

Hence, the results of this study reveal that institutions aim to offer various kinds of explicit and implicit CES. Explicit and implicit CES are both needed to make ethics part of the daily work of professionals:

“This is an important issue about which we talk a lot: how to bring ethics in the veins of the organization?” (Mental health care, managing director).

DISCUSSION

Explicit and implicit CES address ethical issues in different ways. Respondents stress the importance of both and report that they can reinforce each other. Explicit CES places the ethical dimension of care structurally on the organizational agenda in a professional way, with formal tasks and responsibilities. This strengthens both the place and the professional quality of ethics in the organization. Implicit CES offers health care professionals the opportunity to discuss and integrate moral issues in their common practice in an organic way.

Explicit and implicit CES are complementary. Explicit CES is needed as it facilitates systematic and structured attention for the ethical dimension of care on a professional way, with formal tasks and responsibilities. It strengthens the place of ethics in general in the organization and contributes to organizational learning cycles by drawing lessons from incidents and individual ethics cases to the organizational level. Implicit CES is needed as the ethical dimension of care emerges in a natural, more narrative way. It stays close to the actual experience of the ethics of daily care of health care professionals and provides answers to concrete issues, arising in specific settings. Many moral problems are continuous in nature and require explicit as well as implicit kinds of CES to identify them.

Explicit CES is planned and structured, and has a formal character. As such it is suited to deal with clear-cut moral dilemmas and decisions. When it comes to fostering moral awareness and a reflexive attitude, or an ethical climate, more is needed. Implicit CES helps to anchor values and norms which are addressed by explicit CES in the organization as a whole. Structure and culture need to correspond, and cultural change is as important as structural change. This view is in line with literature from organization studies (Flynn & Andersson 2012; Martin 2000). Change cannot be realized by policy alone, particularly when cultural change is at stake (Chapin; 2010).

Recommendations

Managing directors and ethics professionals underline the importance of both explicit and implicit CES, and see the need for constructively combining implicit and explicit ethics support. This has consequences for organizing CES in health care organizations. When

implementing CES, health care institutions should not merely focus on establishing explicit kinds of CES, but use existing implicit kinds of CES and acknowledge them as valuable. Taking into account the activities and professionals involved in implicit kinds of CES not only creates a social basis for explicit kinds of CES, but also allows integration from the start. More research on how to combine explicit and implicit forms of CES in a constructive way is required.

MCD could play a specific role in combining and integrating implicit and explicit forms of CES in health care. MCD is explicitly focused on the concrete experience of health care professionals and aims at reflecting on moral issues in the concrete working place, thereby focusing on experiences of and reflection by health care professionals themselves (Molewijk et al. 2008). MCD thus stays close to the narrative characteristics of implicit CES. At the same time, by the use of method and professional facilitation of moral reflection, MCD is an explicit form of CES that supports professionals to enlarge their moral reflection skills. Furthermore, results of MCD can be placed on the agenda of an institutional ethics committee when the issue has a broader importance. Further experiences with and research on the role of MCD in connecting implicit and explicit CES can help to find new ways to improve ethics support in health care organizations.

Strengths and weaknesses of the study

The strength of this study is the combination of quantitative and qualitative methods and the iterative way of working through the analysis of the data, aiming at verifying results and interpreting them in various, complementary, rounds. Another strength is that all health care institutions were approached, and a considerable number participated in our study. A limitation is that the respondents (i.e. managing directors and ethics staff) may have given a more positive picture on the prevalence and importance of CES when compared to the non-respondents.

CONCLUSION

In the Netherlands, ethics committees are important vehicles for explicit CES, especially in hospitals. A second important kind of explicit CES is MCD, which can be found in half of Dutch health care institutions, and in two third of institutions for mental health care. Ethics consultants play a minor role in all contexts of Dutch health care. The perceived value of explicit CES is that it places the ethical dimension of care structurally on the agenda.

Implicit CES is to be found in all Dutch health care institutions. In mental health care, group meetings as form of implicit CES are more prominent than individuals (in the other contexts this is the other way around). Implicit CES is valued because it fosters attention for the ethical dimension of care in a more organic and narrative way.

In Dutch health care, combining implicit and explicit CES is considered to be a good way to integrally embed ethics in the organization. This opens new perspectives on the meaning, positioning and ownership of ethics in general and CES in particular. We recommend additional research, to investigate: a) the functioning and quality of implicit kinds of CES; b) the way in which implicit and explicit CES can be integrated, including

MCD as possible bridge; and c) the tasks and roles of clinical ethicists in combining implicit and explicit CES.

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REFERENCES

- Aroskar, M. A. (1987). The prevalence and design of ethics committees in nursing homes. *J Am Geriatr Soc*, 35(11), 1028-1033.
- Bamford-Wade, A., Moss T. (2010). Transformational leadership and shared governance. An action study. *Journal of nursing management*, 18(7): 815-21.
- Bolmsjo, I.A., Edberg A.K., Sandman, L. (2006) Everyday ethical problems in dementia care: a teleological model. *Nurs Ethics*, 13(4):340-59.
- Brown, B. A., Miles, S. H., & Aroskar, M. A. (1987). The prevalence and design of ethics committees in nursing homes. *J Am Geriatr Soc*, 35(11):1028-1033.
- Browning, D.M. (2011). Study for common things: cultivating moral sense making on the front lines of practice. *J Med Ethics*, doi:10.1136/medethics-2011-100084.
- Chapin, M.K. (2010). The language of change. Finding words to define culture change in long-term care. *Journal of Aging, Humanities and the Arts*, (4): 185-99.
- Cox, B., & Roy, M. M. (1985). Nursing ethics can improve quality long term care. Forming an Ethics Committee. *J Am Health Care Assoc*, 11(6), 48-51.
- van der Dam, T. Abma, A. Molewijk, M. Kardol, J. Schols, G. Widdershoven. (2011). Organizing Moral Case Deliberation in mixed groups: experiences in two Dutch nursing homes. *Nurs ethics*, 18(3):327-40
- van der Dam, S., Abma, T.A., Kardol, M.J.M., Widdershoven, G.A.M. (2012) 'Here's My Dilemma.' Moral Case Deliberation as a Platform for Discussing Everyday Ethics in Elderly Care. *Health Care Anal*, 20(3):250-67.
- van der Dam, S. (2013). Ethics support in institutional elderly care: a review of the literature. In: *Ethics support in elderly care*. University press Maastricht.
- van Dartel, J. N., Jacobs, M., Jeurissen, R.J.M. (2002). *Ethiek bedrijven in de zorg. Een zaak van het management*. Gorcum bv, Assen.
- Dorries, A. (2007) Die Implementierung Klinischer Ethikberatung in Deutschland. Ergebnisse einer bundesweiten Umfrage bei Krankenhäusern. *Ethik Med*, 19:148–156.
- Flynn, A., Anderson, C. (2012). Meaningful collaboration. *Nursing management*, 43(12) 2-4.
- Forde, R., Pedersen, R. (2011). Clinical Ethics Committees in Norway: What Do They Do, and Does it Make a Difference? Special Section: Bioethics beyond borders. *Camb Q Health care Ethics*, 20:389-95
- Fox, E., Myers, S., Pearlman, R. (2007). Ethics consultation in United States Hospitals: a national survey. *Am J Bioeth* (7), 13-25.
- Greenfield, Jensen (2010). Understanding the lived experiences of patients. Application of a phenomenological approach to ethics. *Physical Therapy*, 90 (8), 1185-97.
- Horner, R., Kelly, T.B. (2007). Ethical decision-making in the helping profession: a contextual and caring approach. *J Relig Spiritual Soc Work*, 26(1), 71-88.
- Martin, M. (2000). *Meaningful work. Rethinking professional ethics*. New York, Oxford University Press.
- Mertens, D.M. (2010). *Research and evaluation in Education and Psychology. Integrating Diversity with quantitative, qualitative and mixed methods*. Thousand Oaks, California: Sage publications.
- Molewijk, B., Abma, T., Stolper, M., Widdershoven, G.A. (2008). Teaching ethics in the clinic. The theory and practice of moral case deliberation. *Journal of Medical Ethics*, 34, 120-124.

- Powers, B.A. (2005). Everyday ethics in assisted living facilities: a framework for assessing resident-focused issues. *J Gerontol Nurs*, 31(1), 31-7.
- Reiter-Theil, S., Mertz, M., Schurmann, J., Stingelin Giles, N., Meyer-Zehnder, B. (2011) Evidence-competence-discourse: the theoretical framework of the multi-centreclinical ethics support project METAP. *Bioethics*, 25, 403-412.
- Roberts, M. (2004). Psychiatric ethics. A critical introduction for mental health nurses. *Journal of psychiatric and mental health nursing*, 11(5), 583-38.
- Slowther, A. (2007). Ethics Consultation and Ethics Committees. In: *Principles of health care ethics*. Wiley & Sons. 527-534.
- Slowther, A., Johnston, C., Goodall, J., Hope, T. (2004). Development of clinical ethics committees. Support for dealing with ethical issues in clinical practice should be an integral part of patient care. *BMJ*, 2, 328-950.
- Slowther, A., Bunch, C., Woolnough, B. (2001). Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. *J Med Ethics*, 27, 2-8.
- Slowther, A.M., McClimans, L., Price, C. (2012). Development of clinical ethics services in the UK: a national survey. *J Med Ethics*, 38, 210-214.
- Svantesson, M., Lofmark, R., Thorsen, H. (2008). Learning a way through ethical problems: Swedish nurses' and doctors' experiences from one model of ethics rounds. *J Med Ethics*, 34, 399-406.
- Weidema, F.C., Molewijk, A.C., Kamsteeg, F., Widdershoven, G.A.M. (2013). Aims and harvest in moral case deliberation. *Nursing ethics*. Accepted dec. 2012.
- van Willigenburg, T., Verweij, M., Kleemans, C.H.M., Kloot-Meijburg, van der H.H. (1991). Ethiek, levensbeschouwing en het management in instellingen voor intramurale gezondheidszorg. *Nationaal Ziekenhuisinstituut, Utrecht*, 109-110.
- Youngner, S.J., Jackson, D.L., Coulton, C., Juknialis, B.W., Smith, E.M. (1983). A national survey of hospital ethics committees. *Crit care med*, 11, 902- 905.

Chapter 3



Prevalence and Characteristics of Moral Case Deliberation in Dutch Health Care

L. Dauwerse, M. Stolper, G. Widdershoven, B. Molewijk
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ABSTRACT

The attention for MCD has increased over the past years. Previous research on MCD is often written from the perspective of MCD experts or MCD participants and we lack a more distant view to the role of MCD in Dutch health care institutions in general. The purpose of this paper is to provide an overview of the state of the art concerning MCD in the Netherlands. As part of a larger national study on CES in the Netherlands, we will focus on the prevalence and characteristics of MCD in Dutch health care. A mixed methods design was used in which we combined two survey questionnaires (sent to all health care institutions), two focus groups and 17 individual interviews with top managers or ethics support staff. The findings demonstrate that MCD is prominent in mental health care, care for people with an intellectual disability, and hospital care. Institutions with MCD differ from institutions without MCD concerning size, kind of problems and importance of ideological background. Characteristic of MCD is that it often exists for 3 years or more, has a high participation of health professionals and middle managers and is both organized scheduled as unscheduled. 'Integration in existing policy' and 'key persons' emerge as important issues in relation to the positioning of MCD. We conclude that MCD is a common part of an integrated ethics policy in Dutch health care and serves as a (bottom up) catalyst for such an integrated ethics policy.

Key words: moral case deliberation, clinical ethics support, national survey, mixed methods, implementation, Dutch health care

INTRODUCTION

Moral case deliberation (MCD) is a specific kind of clinical ethics support, in which a trained facilitator uses a specific method to support a group of health care professionals in their reflection on and analysis of a concrete case (Molewijk et al., 2008a). In the Netherlands, the attention for and the actual use of MCD as a type of clinical ethics support has increased over the past years. In 2006, the national Centre for Ethics in Health Care (CEG) concluded, on the bases of a research report, that the knowledge and skills of health care professionals and health care institutions is limited when it comes down to recognizing and dealing professionally with moral issues. The CEG advised the Dutch government to stimulate both health care institutions and health care education programs to build up expertise of dealing with moral issues (among others with MCD). Since 2005, once or twice a year, a national MCD platform meeting is organized at the Dutch ministry of Health during which MCD experts meet and share experiences. Also since 2005, almost every year, a national working conference on MCD is organized with specific topics and various participants. Recently, as a consequence of a growing number of trained MCD facilitators, a national network for MCD facilitators has been set up. Various Dutch health care institutions have started MCD implementation or MCD training projects, often together with trainers and researchers from universities. More and more health care institutions, in various health care domains, develop MCD expertise and organize MCD meetings.

As a consequence, Dutch and English articles about experiences with MCD have been published. General descriptions of MCD and its theoretical roots in pragmatic hermeneutics and dialogical ethics are described by Abma et al. (2009) and Widdershoven & Molewijk (2010). Evaluation studies of both MCD sessions and MCD implementation projects in two different mental health care institutions reported that participants were positive about MCD (Molewijk et al., 2008b/c). However, implementation of MCD causes ongoing challenges. Various implementation reports pay attention to the roles of local coordinators of MCD, participants of MCD, and managers in organizing MCD (Weidema et al. 2011,2012,2013). Experiences with MCD in an academic hospital and in elderly care have been reported (respectively Stolper et. al., 2012, and Van der Dam, 2011,2012). Training programs for facilitators have been evaluated, showing that participants were positive about the training and had trust in their competence (Plantinga, 2012). Other studies have been published about MCD methods (Steinkamp & Gordijn, 2003; Molewijk & Ahlzen, 2011a) or the role of emotions in MCD (Molewijk et al., 2011b/c).

Most of these publications focus on local or institutional initiatives. Although a local focus is useful for a detailed insight of how MCD works in a specific context, it does not provide insight into the prevalence of MCD in the various domains of Dutch health care (i.e. hospital care, mental health care, elderly care, care for people with an intellectual disability). There have been two nation-wide studies in the Netherlands regarding clinical ethics support earlier (Van Willigenburg et al., 1991; Van Dartel et al., 2002) but they did not report on (the prevalence of) MCD. Given the increased attention for MCD in the last 10 years, new and more detailed prevalence information is needed. How many health care institutions organize MCD? What are their characteristics, and in which domains of health care are they situated? Since how long do they use MCD as clinical ethics support? How often are MCD

sessions organized and in which way? Who participate in these MCD sessions? How is MCD positioned within the health care institutions? This paper will address these questions.

Prior publications on MCD are often written from the perspective of MCD experts or MCD participants. In some publications (Weidema et al., 2012), health care professionals and managers are involved in evaluating MCD as clinical ethics support. Yet, most of the studies that are reported come from institutions that were motivated to start with MCD and to study it. This may result a positive bias towards MCD practices. We lack a more distant view to the role of MCD in Dutch health care institutions in general. Furthermore, we do not know how managing directors of the health care institutions think about MCD in their institutions, and whether this differs from the views of staff responsible for organizing ethics support services.

In this paper we give an overview of the state of the art concerning MCD in the Netherlands. As part of a larger national study on CES in the Netherlands, we will focus on the prevalence and characteristics of MCD in Dutch health. We first briefly describe the core features of MCD in comparison to other forms of clinical ethics support. Then we explain the mixed methods research design of our study, which combined questionnaires, interviews and focus groups. Next, we present results from this study, focusing on: 1) prevalence of MCD in Dutch health care; 2) characteristics of Dutch health care institutions with MCD; 3) characteristics of how MCD is organized; and 4) information about how MCD is positioned within the organization. We will discuss the results, referring to literature on MCD. We end with strengths and limits of this study, the central conclusions and some suggestions for future research on MCD.

Moral case deliberation as clinical ethics support

A moral case deliberation consists of a meeting with health caregivers who systematically reflect on one of their moral questions within a concrete clinical case from their practice (Molewijk et al., 2008a). It focuses on concrete moral issues: ‘What should we consider as the morally right thing to do in this specific situation and how should we do it rightly?’ However, also more philosophical, for example conceptual and virtue-based questions are at stake (e.g. ‘What does understanding mean?’ and ‘When am I a good professional?’) (Abma et al., 2009). Four central, often co-existing, goals of moral case deliberation are: (1) to reflect on the case and to improve the quality of care within that case; (2) to reflect on what it means to be a good professional and to enhance professional’s moral competencies; (3) to reflect upon what good multidisciplinary cooperation means in light of the quality of care; and (4) to reflect on institutional or organizational issues and improve the moral quality of care at that level (i.e. use insights from MCD for policy, guidelines, cultural change, etcetera).

The reflection, which takes 45 minutes to 2 hours, is facilitated by a trained facilitator and structured by means of a selected conversation method (for examples of conversation methods see: Steinkamp & Gordijn, 2004; Kessels et al., 2008, 2009; Molewijk et al., 2008a; Molewijk & Ahlzen, 2011). The facilitator, an ethicist or someone who is trained in clinical ethics and conversation methods, does not give substantial advice and does not morally justify or legitimize a specific decision (Stolper et al., 2012). The expertise of the facilitator consists of, among other things, fostering a sincere and constructive dialogue among the participants,

keeping an eye on the moral dimension of the case, supporting the joint reasoning process, and helping the group in planning actions in order to improve the quality of care. Methods are chosen because of the specific goal of a moral case deliberation.

Moral case deliberation differs significantly from clinical ethics consultation (Abma et al., 2009). With respect to ethics consultation, the ASBH taskforce on the Core Competencies for Health Care Ethics Consultation describes a more procedural and expert approach of the ethics consultant when discussing ‘the ethics facilitation approach’. A central goal of the ethics consultant is to answer the question “Who is the appropriate decision maker?” Specific attention is being paid to the knowledge from existing policy, guidelines and law (ASBH, 1998; Aulisio et al., 2003). Even though both approaches facilitate moral reasoning, it seems as if the ethics consultant focuses more on the answer of the question ‘What is morally right according to existing knowledge from policy, guidelines and law?’ while the MCD facilitator focuses more on how the MCD participants constitute concepts of and arguments for morally good care through dialogical processes

METHODS

By post, we asked managing directors of all (i.e. 2147) Dutch health care institutions (hospitals, mental health care institutions, elderly care institutions, and institutions for people with an intellectual disability) to participate in a national survey questionnaire (SQ 1). Managing directors included board members, directors and location managers. Respondents were also asked to provide contact information of ethics support staff within their institution, if present, for a second national survey, web-based, questionnaire (SQ 2). Ethics support staff are employees who organize ethics support, for example ethics committee chairs. Further qualitative data were assembled through interviews and focus groups, with professionals involved in CES (including managing directors, staff employees, and bioethicists) from various health care domains.

Survey 1

The first survey (SQ 1) was organized between December 2007 and December 2009. A postal questionnaire was developed in close connection with experts in the field of CES (n = 7). The questionnaire was tested with 9 participants. Considerable refinements were made to the survey tool (particularly to the length) and the introductory explanation. After the first round, two reminders were sent. The questionnaire addressed various kinds of ethics support, with specific attention for moral case deliberation.

Interviews and focus groups

Following the first survey (Sept 2008), five interviews were conducted with managing directors and ethics support staff members to complement and get further insight in the data of the findings of the questionnaire. In addition, two focus groups with 22 managing directors and ethics support staff members were organized in June and July 2009 in order to complement and finalize the results of the first survey. In these focus groups advantages and disadvantages of moral case deliberation were discussed.

Survey 2

The second survey (SQ 2) took place between September 2008 and September 2010. A digital questionnaire was developed, based on interviews and discussions with experts (n = 12). The questionnaire was designed via a web-based, flexible and secure survey development tool (enqueteviainternet.nl). It was pre-tested with 12 participants. The content of several questions of the second questionnaire had already been tested in the pilot of questionnaire 1, which further supported the face and content validity of the questionnaire.

The second questionnaire included a question about the prevalence of MCD, several questions for institutions in which MCD was absent or deemed not important, and 23 questions about the characteristics of MCD for institutions in which MCD was considered important. The second questionnaire was addressed to the ethics support staff members who were mentioned by the respondents of questionnaire 1. Two reminders were sent.

Interviews

After the second survey questionnaire, twelve individual interviews were conducted with ethics support staff members and managing directors from institutions with (a combination of): 1) an ethics committee, 2) moral case deliberation, 3) ethics consultation, and 4) implicit kind of CES (peer-supervision). These interviews aimed to help interpret and reflect on the survey findings. The interviews focused on the experiences and views of interviewees concerning the specific CES which was present in their institution.

Analysis

Both questionnaires consisted of closed and open questions; the results were analyzed using quantitative and qualitative methods. SPSS 15 and Excel were used to analyze the responses to the closed questions; responses to the open questions were explored through content analysis to identify common themes and key issues. Quantitative and qualitative data were compared and discussed within the research team. Throughout this process, emerging patterns and hypotheses were developed and checked, resulting in a refinement of the analyses. To confirm the analyses, individual member checks with interviewees and focus groups participants were performed.

Interviews were transcribed. Initial coding was performed in line with quality criteria described in the literature, remaining open, staying close to the data and keeping codes simple and precise (Mertens, 2010). We constructed short codes, compared data, and involved team members in the coding when appropriate. We discussed differences in interpretation and use of the codes, revised codes if necessary and made a codebook that included brief descriptions of each code which facilitated a constant comparative method of analysis (Mertens, 2010).

The first and second author collaborated in the phase of focused coding. This required decisions about which initial codes made the most analytical sense to categorize the data incisively and completely. During the analysis, all authors discussed the categories until consensus was reached.

Response rate

During data collection it turned out that the initial 2137 individual health care institutions were members of 864 legal bodies (umbrella organizations with a legal status). As a consequence, there are two response rates for this first questionnaire, namely 30% (638 / 2137) at the individual institution level and 56% (485 / 864) at the legal body level. Respondents included board members, directors and location managers. In this article we refer to them as ‘managing directors’.

The (digital) second questionnaire was sent by email to all the ethics support staff members (N = 515) designated by the respondents in questionnaire 1. The number of ethics support staff members was less than the number of respondents for questionnaire 1 (N=638) because not all respondents in questionnaire 1 designated an ethics support staff member. The response rate of the second survey questionnaire was 48% (247 / 515). Respondents included mainly ethics support staff such as spiritual caregivers, but in some cases also representatives from management.

RESULTS

The results are ordered in four sections. First, we present the prevalence of MCD in healthcare institutions, related to other forms of CES, and the perceived importance of MCD in healthcare institutions with MCD. Second, we compare characteristics of Dutch healthcare institutions with MCD with those of institutions without MCD. Third, we describe characteristics of MCD in Dutch health care institutions in which MCD is deemed important. Fourth, we describe how MCD is positioned within the organization. For the prevalence, we use data from the second questionnaire, directed at ethics support staff. Ethics support staff report higher prevalence of CES than managing directors. We consider the data of ethics support staff more reliable, because they know more about CES in daily practice in the institution. For the perceived value, we use data from interviews and focus groups with managing directors as well as ethics support staff.

1. Prevalence of MCD in Dutch health care

In this section we will present: A) prevalence of MCD in general, B) prevalence and importance of MCD in different health care domains and C) prevalence of MCD, combined with other kinds of CES, in different health care domains.

A. Prevalence of MCD in Dutch health care in general

According to ethics support staff, MCD is present in 44% of Dutch health care institutions (see table 1). This is more than ethical consultation (15%). It is less than ethics committees (51%) and implicit forms of CES (90%).

Table 1: CES in Dutch health care institutions in general (N = 247)

	N	%
MCD	109	44%
Ethics committee	125	51%
Ethics consultant	36	15%
Implicit CES	224	90%

B. Prevalence and importance of MCD in different health care domains

MCD is prominent in mental health care, care for people with an intellectual disability, and hospital care. In these domains it is mentioned as present in the organization by respectively 62% , 58 %, and 54% of the respondents (see table 2). In elderly care, 36% of the ethics support staff members mentioned MCD as present in the organization.

Table 2: Prevalence MCD in various health care domains (N= 247)

Sector/ CES	MCD present		Besides MCD, also present:					
	Total 109		Ethics committee		Ethics consultant		Implicit CES	
	N	%	N	%	N	%	N	%
Elderly care (N=131)	49	37%	35	74%	6	13%	34	72%
Hospital (N = 46)	25	54%	20	80%	7	28%	22	88%
Mental health care (N=29)	18	62%	8	44%	4	22%	16	89%
Care intellectual disability (N = 36)	21	58%	14	67%	5	24%	18	86%

We also asked ethics staff members whether MCD is important in the organization. In almost half of the health care organizations in which it is present, MCD was regarded as important by the respondents. If we look at the health care domains, we see that MCD is considered important in more than 60% of the mental health care institutions in which it is provided. In care for people with an intellectual disability, MCD is important in almost half of the institutions in which it is present. In elderly care and hospital care, in less than 40% of the institutions with MCD, it is regarded as important.

Table 3: Importance of MCD in the organization

Sector / CES	MCD is important in the organization (n = 52 of 109)	
	N	%
Elderly care (n=131)	21	16%
Hospital (n = 46)	9	20%
Mental health care (n=29)	11	38%
Care intellectual disability (n = 36)	10	28%

C. *Prevalence of MCD, combined with other kinds of CES, in different health care domains*

MCD can be combined with other kinds of explicit CES (see table 2). It is mostly combined with ethics committees especially in hospital care and elderly care. Our qualitative findings confirm that various kinds of explicit CES are combined:

“The preferred institutional policy is to stimulate ethical reflection through moral case deliberation. The ethics committee is asked for ethical advice.” (MCD facilitator and ethics committee member, , Elderly care).

Also the combination of MCD with implicit CES is highly prevalent (see table 2).

“We combine moral case deliberation with regular policy meetings at the ward. In the latter, we do not use the method of MCD, but focus on policy issues, involving ethical aspects.” (MCD facilitator, hospital).

2. Characteristics of Dutch health care institutions with MCD

In this section, institutions with MCD and without MCD are compared, using data provided by ethics support staff (SQ2). We will focus on size, type and identity of the institutions (table 4). MCD is less frequent in small institutions than in large institutions. MCD is present in 31 % of institutions with under 500 employees, and in 54% of institutions with 2000 or more employees. MCD is more often to be found in institutions with 500-1000 employees (54%) than in institutions with 1000 – 2000 employees (45%). Regarding kind of problems, MCD is present in 85% of the institutions which indicate they mainly have acute problems. Related to ideological (religious or worldview / philosophical) background, MCD is less present in institutions in which the ideological background is unimportant (37%) than in institutions in which it is important (63%).

Table 4: Comparison of health care institutions with and without MCD

	Hc institutions with MCD (n = 109)		Hc institutions without MCD (n = 138)	
	%	N	%	N
Number of employees				
2000 or more (n = 59)	54%	32	46%	27
1000-2000 (n = 55)	45%	25	55%	30
500-1000 (n = 37)	54%	20	46%	17
0-500 (n = 85)	31%	26	69%	59
Kind of problems	%	N	%	n
Mainly chronic disease (n = 166)	39%	64	61%	102
Equal division of acute and chronic disease (n = 62)	50%	31	50%	31
Mainly acute (n = 13)	85%	11	15%	2
Ideological background important?	%	N	%	n
Yes (n = 111)	53%	59	47%	52
No (n = 104)	37%	38	63%	66
Do not know (n = 19)	32%	8	58%	11

3. Characteristics of MCD in Dutch health care institution

Respondents who reported that MCD was not only present, but also important in their organization (N=52, see section 1B and table 3 above), were asked further questions about A) period of existence, B) number and background of participants in MCD, and C) frequency of (scheduled and unscheduled) MCD meetings. In this section we present the data from these questions.

Table 5: Characteristics of MCD in institutions that have MCD and in which MCD is deemed important (n = 52)

Characteristics	%	N
1. Period of existence		
3 or more years	56%	29
0-2 years	19%	10
stopped	2%	1
no answer	25%	13
2. Average number of participants in MCD sessions		
4 to 6	23%	12
7 to 9	29%	15
10 or more	21%	11
No answer	27%	14
3. Average number of scheduled MCD sessions per MCD group		
1-4 times a year	27%	14
5-8 times a year	17%	9
8 or more times a year	8%	4
Different numbers of scheduled meetings for different groups	6%	3
No scheduled meetings (only ad hoc)	15%	8
no answer	27%	14
4. Number of unscheduled (ad hoc) meetings for an MCD group		
1-4 times a year	42%	22
5-8 times a year	13%	7
8 or more times a year	15%	8
no unscheduled meetings	6%	3
no answer	23%	12

A. Number of years of MCD existence

In the majority (56%) of health care institutions in which MCD is important, it exists for more than three years. Our qualitative data show that it takes time to put MCD on the agenda of the organization and get people interested:

“MCD started during the period in which there was interest in reducing the use of coercion and restraint, that movement was very strong here. After three years there was a regression. We took a new initiative two, three years ago, and it appears to enter a next phase now.” (Managing director, mental health care).

It also takes a long time before MCD is part of organizational policy:

“It took nine years before a policy decision was made, stating that our institution prefers MCD as an instrument” (MCD conversation leader, ethics committee member, care for people with an intellectual disability).

B. Number and background of MCD participants

Most MCD meetings (29%) have 7- 9 participants (see table 5). There are also smaller meetings, with 4-6 participants (23%), and larger ones with 10 or more participants (21%). In all institutions, MCD meetings are multidisciplinary. The participation of professional caregivers (nurses, physicians and nursing aids) is relatively high (respectively 56%, 48% and 48%) (table 6). The participation of professionals who have a training in ethics, for example spiritual caregivers, ethicists, and legal experts, is considerably less than that of health care professionals (respectively 38%, 19%, and 4%). The participation of patients and their family within MCD is relatively low (respectively 10% and 17% of MCD meetings). The participation of middle managers (54%) is relatively high, compared to the rather low participation of (location) managers (19%), board members (15%) and directors (10%).

Table 6: Background participants (n = 52)

	BACKGROUND OF MCD PARTICIPANTS		
		% Yes	N Yes
Professional care givers	Nurse	56%	29
	Physician	48%	25
	Nursing assistant	48%	25
Management	Middle manager	54%	28
	(Location) manager	19%	10
	Board member	15%	8
	Director	10%	5
Staff	Spiritual care giver	38%	20
	Ethicist	19%	10
	Staff employee	19%	10
	Law specialist	4%	2
Patient / family	Family	17%	9
	Patient	10%	5

In the interviews, some respondents complain about the low participation of physicians in MCD: *“For most physicians the outpatient ward and the operation room always have priority”*; *“The participation of physicians is limited, much too limited.”* The quantitative data do not seem to support these complaints, since physicians are relatively often mentioned as participants. The difference between quantitative and qualitative data may be not that large, since it might be the case that only a small number of physicians participates in MCD (or always the same physician who is involved and acknowledges the relevance of the perspective of a physician in MCD).

The relatively low presence of spiritual caregivers and ethicists in MCD might be related to their traditional role of providing normative guidance, rather than focusing on moral experiences of health care professionals. During an interview, a respondent says:

“I have the idea that when a spiritual caregiver grabs hold of ethics too fast, people immediately see it is to claim a position and responsibility. That will not lead to success ” (spiritual caregiver, mental health care).

Respondents in the interviews confirm that the participation of patients in MCD is low. Some say this is a conscious choice, as MCD is seen as a means for reflection and dialogue between professional care givers:

“No, they [patient and family] are not present. We say that a good conversation or good communication with patients and family should meet other quality criteria than MCD within the team. MCD should be an instrument for the team, to deliberate on what they think is moral desirable or see as a moral acceptable action. The team should have some room for this, to talk, to say what they think, without having to translate this to patient and family.”(MCD conversation leader, ethics researcher, hospital)

Other respondents think it is desirable that patients participate in MCD:

“It would be desirable to involve family in it [= MCD]. We, for example, organized thematic meetings about autonomy and sexuality. For some of them we also invited patients; both patients and employees. And that [patient participation] was very good and clarifying. [...]”(Board secretary, mental health care).

C. Prevalence of scheduled and unscheduled meetings

MCD meetings can both be scheduled (organized in a regular basis within a team), or ad hoc (organized when a specific case requires deliberation). In half of the institutions which report scheduled meetings, MCD groups are planned 1-4 times a year; in the other half, groups meet more than 4 times a year. In interviews, respondents mention as advantage of scheduled meetings that they stimulate continuous learning cycles and contribute to moral competence:

“Ultimately, ethics is about ‘how should we relate to each other and to the world around us?’, and to reflect on that. So education is on-going and permanent for that matter. It is important that there is willingness to reflect on one’s attitude. Scheduled meetings can stimulate this process, but are no ‘sine qua non’ ” (Ethics support staff, institution for people with an intellectual disability).

For ad hoc meetings, the numbers are similar to those of scheduled meetings. In almost half of the institutions which report these meetings, ad hoc meetings take place in a team 1-4 times a year, in the other half, more than 4 meetings a year are requested by a team.

Respondents see as an advantage of ad hoc meetings, that they allow professionals to bring up burning issues to be discussed in an MCD session immediately:

“As soon as a dilemma or problem in the care around a patient arises, the MCD facilitator is contacted.” (MCD facilitator and ethics committee member, care for people with an intellectual disability).

In circa 80% of the institutions which report scheduled and/or unscheduled meetings, both are present. This means that a series of meetings is planned, but that ad hoc meetings of the MCD group are organized when a specific case comes up which cannot wait until the next scheduled meeting. Respondents in the interviews say this combination is useful, because it stimulates regular reflection, but also enables a quick response to sudden difficult cases.

4. Positioning MCD in the institution

Both in the questionnaires and the interviews and focus groups, the topic of positioning MCD in the organization was addressed. In this section we present data on positioning of MCD in relation to institutional policy and structures, and the role of key persons in giving MCD a recognizable position in the institution.

A. MCD and organizational policy

About one third of the respondents who gave an answer to the question whether MCD is related to institutional policy (leaving the ‘no answer’ group out), mentioned that MCD is part of a long term policy project within the organization, and is not seen as a temporarily activity (table 7).

Table 7: Positioning MCD (N = 52)

	%	N
Connection to institutional policy		
MCD is part of a long term policy	25%	13
MCD is organized at institutional level	19%	10
MCD is organized at ward level	10%	5
MCD is organized ad hoc	17%	9
No answer	21%	11
Connection to organizational structures		
Yes	37%	19
Sometimes	19%	10
No	17%	9
No answer	27%	14

In the responses to the questionnaire for ethics support staff (SQ2), examples are mentioned: ‘*Ethics policy connected to projects like experience oriented care and small scale living*’ (MCD conversation leader, ethics consultant, spiritual caregiver, elderly care)

Integrating MCD in a long term policy increases the impact of ethics in the organization as a whole. In an interview, a director explains the success of MCD in his mental health care institution by referring to the connection of MCD to organizational themes like the reduction of coercion and restraint. When MCD is not a part of a long term policy, there is always a threat that MCD is being overruled by other priorities. Ethics support staff says they continuously struggle to keep MCD on the agenda. Connecting MCD to other long term policies or structures (like quality policy of the quality management staff) helps them to anchor MCD within the institution: *“Make sure that MCD is anchored in quality policy.”* (Ethics expert supporting MCD in organisations).

A managing director explains that giving employees an MCD training contributes to the internal quality procedure:

“Currently we have trained about 25 people as facilitator of MCD. Then it spreads through the organization, people learn to, or at least try, to have a dialogue. Within the frame of internal quality development that has value. It belongs to quality policy. Because quality is essentially an ethical issue. You want to do something good, to make it better than it was.” (Managing director; mental health care).

An ethics committee member in elderly care explains that connecting MCD to a larger project around professionalization, contributed to its visibility:

“As part of the professionalization project, a sort of market was organized, in which we offered two MCD workshops. The attendance was high, we were evaluated good and the participants were very diverse, including middle managers and care workers.” (Ethics committee member; elderly care)

B. MCD and organizational structures

In SQ 2, we asked whether MCD is connected to organizational structures. Of the respondents who answered this question (again leaving the ‘no answer’ group out), more than 80% mentioned that such a connection exists (see table 7). In the answers to the open ended questions in SQ2, the ethics committee is often mentioned as a relevant structure. This is in line with the results presented in section 1 above, showing that MCD is often combined with other forms of CES, especially with an ethics committee. Whereas the results of section 1 showed that both MCD and the ethics committee exist together, the answers here indicate that both are actually related to one another (and thus do not operate independently). Respondents in interviews and focus groups underline the importance of integrating various ways of CES. An expert in organizing ethics explains in an interview that MCD and an ethics committee are complementary, and can and should reinforce one another:

“MCD is another kind of ethics than an ethics committee which, for example, makes normative pronouncements. And I think both kinds of ethics are desirable. And a combination between them.” (Expert in organizing MCD in various contexts)

The aims of both forms of CES differ according to this respondent. MCD focuses on supporting professional care givers, whereas an ethics committee provides institutional guidelines:

“MCD really is supporting professionals, it is not normative, which implies that the ethicist does not guide the content and does not say ‘this is how it should be.’ But an ethics committee can and probably should do that in a hospital, and conclude for instance: ‘This is not proper informed consent, this was poor.’ ” (Expert in organizing MCD in various contexts)

By connecting MCD to the ethics committee, outcomes of deliberations on concrete cases can be translated into institutional policy in general. Respondents state that this is important in order to generate moral learning in the institution:

“It is important to] translate the outcomes of MCD to vision and policy’ (Spiritual caregiver, elderly care)

“What is learned during MCD, is too little translated to learning at organizational or policy level. It tends to be confined to nice conversations in a team, without learning in a broader way. Sometimes not even within the team, and certainly not within the division or institution.” (Expert in organizing ethics, various contexts)

Next to the connection of MCD to the ethics committee, other structures are mentioned, which provide implicit CES, such as : team meetings, structured peer supervision, multidisciplinary team meeting, introduction meetings for medical specialists, contact persons, department meetings, and education of physicians, psychologists and nurses. Respondent in interviews underline the importance of connecting MCD to structures in which ethical issues are addressed more informally and implicitly. Connecting MCD to peer-review and (multidisciplinary) is regarded as especially useful for giving it a firm position in the organisation. A respondent says: *“When ethics is integrated in daily processes, peer-supervision, regular work meetings, it has the greatest chance for success.” (Board secretary, mental health care)*. Integrating MCD in such meetings prevents a separate, ‘yet another’ meeting: *“So, you don’t have to organize a separate meeting from 3 to 5, on Friday afternoon, with a conversation leader. It is integrated in the usual meetings, and makes participants be aware, together, of the ethical dimension of emerging problems.” (Board secretary, mental health care)*.

C. Role of key persons in positioning MCD

Key persons involved in organizing MCD play an important role in positioning MCD in the organization. A hospital medical ethicist, responsible for MCD, explains that he can help to position MCD in his institution because he is a member of the medical staff:

“Through my appointment as medical ethicist and my position within the organization, the board showed it [= ethics] is important for them. [...] I was made a member of the medical staff, and participated in the oncological center. Currently

after two years, I participate in strategic deliberations.” (Medical ethicist, spiritual caregiver and nurse, hospital).

Professionals who are responsible for MCD, as facilitator or organizer, can play an exemplary role, especially if they have a strong link with the work floor. The hospital medical ethicist quoted above, explains that he continues working as a nurse for one day a week, which makes he is seen as ‘one of the nurses’:

“I know many people and because I am also a nurse, I speak the language. They also know me from the work floor.” (Medical ethicist, spiritual caregiver and nurse, hospital).

Interviewees explain that the role of MCD facilitators is essential and is not always recognized as such:

“I say to him [= MCD facilitator]: don’t underestimate your role. Because he doesn’t see that anymore. Often you have to do the work with incompetent people. People who do MCD ‘in name only’. That’s one of the pitfalls of ethics policy and especially of MCD. [...] People who think: ‘well, being a facilitator, everyone can do that.’ Well, people tend to take it for granted but this requires many skills.” (Managing director, mental health care)

Strengths and weaknesses of this study

A strength of this study is that data are not limited to views of MCD experts, or MCD participants, but are provided by managing directors and ethics support staff, in the context of a larger national study on clinical ethics support in general. Another strength is that it combined quantitative and qualitative data. Qualitative data enabled us to deepen and further explain the outcome of the surveys. A further strength is that all health care institutions in various health care domains were addressed for the survey studies.

A weakness is that the results of the survey studies cannot be extrapolated fully, since institutions which did not respond might have less CES in general, and MCD in particular, than responding institutions. A further weakness is that the ethics support staff (SQ 2) was designated by managing directors responding to SQ 1, which means that SQ 2 was not open to all health care institutions. A weakness is also that the prevalence of MCD (and other forms of CES) mentioned by ethics support staff (SQ 2) was higher than that mentioned by managing directors (SQ 1), which shows that various stakeholder groups have different views on the presence of CES in the organization. This means that the data we used from SQ 2 are not corroborated by the data from SQ 1. We decided to use SQ 2, because we assume that ethics support staff is more knowledgeable about the presence of CES than managing directors are. Interestingly, the number of institutions in which MCD is present according to managing directors is more or less in line with the number of institutions in which it is present and deemed important by ethics support staff (see table 3). This may indicate that managing directors are more likely to report the presence of MCD if it is important in the organization

in the eyes of ethics support staff. This may explain the differences in the data on prevalence between SQ 1 and SQ 2, and may also support our decision to use the data from SQ 2.

CONCLUSION AND DISCUSSION

This paper presents results of the first national study on prevalence and characteristics of MCD in Dutch health care institutions, as part of a larger study on different kinds of clinical ethics support (CES) in the Netherlands. Two nation-wide surveys among respectively managing directors and ethics support staff members, and 17 interviews and 2 focus group interviews, provided insight in the current state of the art concerning MCD in the Netherlands. In this section we will discuss central findings and present recommendations for practice and research of MCD.

According to ethics support staff, MCD is present in 44% of Dutch health care institutions. For different health care domains, ethics staff members mention a prevalence of MCD of 62% in mental health care, 58% in care for people with a mental disability, 54% in hospitals, and 36% in elderly care. MCD is regarded as important in 38% of mental health care institutions, in 28% of the institutions for care for people with an intellectual disability, in 20% of hospitals, and in 16% of elderly care institutions. In most of the institutions with MCD, also other kinds of explicit CES are present. For example, ethics committees are most often mentioned as available explicit CES, particular in elderly care and hospitals. This indicates that MCD is not an alternative for ethics committees, but provides an add-on service. Ethics support staff also mentions a high percentage of implicit CES next to MCD. This indicates that MCD does not replace informal interactions on moral questions, but rather acts as a complement to these, enabling structured reflection on moral experiences.

Concerning the characteristics of the institutions: MCD is less present in small institutions (with a maximum of 500 employees) than in larger ones. Furthermore, MCD is more often present in institutions for acute care than in institutions for chronic care. This is not reflected in the current literature, as many articles on MCD focus on MCD in elderly care and (chronic wards in) mental health care (Van der Dam et al, 2011, 2012, 2013; Molewijk et al, 2008b). MCD is more present in institutions in which the ideological background is deemed important. This may indicate that MCD is seen as a means to reflect on and promote institutional values.

MCD is often organized in institutions for a longer period (more than 3 years). This indicates that institutions, once they start with MCD, are dedicated to continue. This is in line with the literature, stressing both that experiences with MCD are evaluated positively, and at the same time that implementing MCD is not a short term activity: it requires a long and creative process (Weidema et al., 2012, 2013).

MCD meetings are interdisciplinary, with participants from various professional groups and from middle management. Nurses often take part in MCD meetings. It is unclear to what degree physicians participate. The quantitative data indicate that they are present in almost half of the meetings. In interviews, respondents say that physicians have comparatively little interest in and time for MCD. Physicians' interest might be higher when they can bring in an acute decisional problem in an ad-hoc MCD session. This subject requires further investigation. Patients and family are relatively absent in MCD meetings; most MCD

sessions are for health care professionals only. For theoretical and normative reasons, patient and family perspectives are relevant in the dialogue on what is or constitutes morally good care (Weidema et al, 2011). The relative absence of patients and family in MCD might be related to concerns of safety and privacy among health care professionals. This is something to explore in further research.

In most institutions in which MCD is found important, both scheduled and unscheduled MCD meetings take place. Both kinds of meetings can complement one another, because scheduled meetings serve as a vehicle for structural reflection on and learning from moral experience in teams, while ad hoc meetings enable deliberation on cases which need instant attention and decision-making. Combining scheduled and unscheduled meetings may be a useful tool for implementing MCD in the organization.

Implementation of MCD can further be improved by combining it with institutional policy issues and integrating it with institutional structures. Relevant structures include quality management and ethics committees (which explicitly aim at ethical reflection and policy making), team meetings and peer supervision. Combining various kinds of explicit and implicit ethics support calls for a clearer vision of an integrated policy for various ethics support activities on several levels within the institution (Reither Theil et al., 2011; Fox et. al, 2010). Furthermore, key persons may foster the visibility of MCD in the organization. As ambassadors of ethics, they can help to further develop an institutional ethics policy, which aims to integrate MCD with relevant structures in the organization and to translate outcomes of MCD into more general normative guidelines. Given the risk that MCD meetings only function as isolated meetings on singular cases, with a limited amount of participants, and with no follow-up at other levels within the institutions, the institutional integration of MCD meetings is crucial. Future MCD research should focus on how to use insights from MCD meetings for professionals who did not participate and for formulating policies or guidelines. How to develop a guideline out of a series of MCD meetings? How to transfer local insights from MCD participants to more abstract policy rules at the institutional level? How to use such policy or guidelines, once developed, in other specific contexts? Qualitative participatory research such as Responsive Evaluation and Action Research might be useful to address these research questions in concrete contexts.

REFERENCES

- ASBH' Task force on standards for bioethics consultation. (1998). Core competencies for health ethics consultation. The report of the American Society for Bioethics and Humanities. ASBH.
- Aulisio, M. P., Arnold, R. M., & Youngner, S. J. (Eds.). (2003). *Ethics consultation. From theory to practice*. Baltimore: The John Hopkins University Press.
- van der Dam, SS., Abma, TA., Molewijk, AC., Kardol, MJ., Schols, JM., Widdershoven, GA. 2011. Organizing moral case deliberation experiences in two Dutch nursing homes. *Nurs Ethics*;18(3):327-40.
- van der Dam, S., Abma, TA., Kardol, MJ., Widdershoven, GA. 2012."Here's my dilemma". Moral case deliberation as a platform for discussing everyday ethics in elderly care. *Health Care Anal*;20(3): 250-67.
- van der Dam, S., Schols, JM., Kardol, TJ., Molewijk, BC., Widdershoven, GA., Abma TA. 2013. The discovery of deliberation. From ambiguity to appreciation through the learning process of doing Moral Case Deliberation in Dutch elderly care. *Soc Sci Med*; 83:125-32.
- van Dartel, J. N., Jacobs, M., Jeurissen, R.J.M. (2002). *Ethiek bedrijven in de zorg. Een zaak van het management*. Gorcum bv, Assen.
- Fox E., Bottrell MM., Berkowitz KA., Chanko BL., Foglia MB., Pearlman RA. Integratedethics: an innovative program to improve ethics quality in health care. *The Innovation Journal: The Public Sector Innovation Journal* 15(2); 8.
- Kessels, J., E. Boers, P. Mostert (2004). *Free space and room to reflect. Philosophy in organisations*. Boom publishers, Amsterdam.
- Kessels, J., E. Boers, P. Mostert (2009). *Free space. Field guide to conversations*. Boom publishers, Amsterdam.
- Molewijk, AC., Abma, T., Stolper, M., Widdershoven, G. 2008a. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *J Med Ethics*;34(2):120-4.
- Molewijk, B., Verkerk, M., Milius, H., Widdershoven, G. 2008b. Implementing moral case deliberation in a psychiatric hospital: process and outcome. *Med Health Care Philos*;11(1):43-56.
- Molewijk, B., Zadelhoff, E., Lendemeijer, B., Widdershoven, G. 2008c. Implementing moral case deliberation in Dutch health care: improving moral competency of professionals and quality of care. *Bioethica Forum*;1(1): 57-65.
- Molewijk, B & Ahlzen, R. 2011a. Clinical Ethics Committee Case 13: Should the school doctor contact the mother of a 17-year-old girl who has expressed suicidal thoughts? *Clinical Ethics*; 6 (1): 5-10.
- Molewijk, B., Kleinlugtenbelt, D., Widdershoven, G. 2011b. The role of emotions in moral case deliberation: theory, practice, and methodology. *Bioethics*;25(7): 383-93.
- Molewijk, B., Kleinlugtenbelt, D., Pugh, SM., Widdershoven, G. 2011c. Emotions and clinical ethics support. A moral inquiry into emotions in moral case deliberation.*HEC Forum*; 23(4):257-68.
- Plantinga, M., Molewijk, B., de Bree, M., Moraal, M., Verkerk, M., Widdershoven, GA. 2012. Training healthcare professionals as moral case deliberation facilitators: evaluation of a Dutch training programme. *J Med Ethics*;38(10):630-5.
- Reither-Theil, S., Mertz, M., Schurmann, J., Stingelin Giles, N., Meyer-Zehnder, B. 2011. Evidence-Competence-Discourse: the theoretical framework of the multi-centre clinical ethics support project METAP. *Bioethics* 25(7): 403–412.
- Steinkamp, N & Gordijn, B. Ethical case deliberation on the ward. 2003. A comparison of four methods. *Med Health Care Philos*;6(3):235-46.

- Stolper, M., Metselaar, S., Molewijk, B., Widdershoven G. (2012). Moral Case Deliberation in an Academic Hospital in the Netherlands. Tensions Between Theory and Practice. *Journal International de Bioéthique*;23(3-4): 53-66.
- Weidema, FC., Molewijk BAC., Kamsteeg F., Widdershoven, GAM. 2013. Aims and harvest of moral case deliberation. *Nurs ethics* . DOI: 10.1177/0969733012473773
- Weidema FC., Molewijk AC., Widdershoven GAM., Abma TA. 2012. Enacting Ethics: Bottom-up Involvement in Implementing Moral Case Deliberation. *Health Care Anal* 20:1–19
- Weidema, FC., Abma, TA., Widdershoven, GAM., Molewijk, AC. 2011. Client Participation in Moral Case Deliberation: A Precarious Relational Balance. *HEC Forum* 23:207–224
- Widdershoven, G & Molewijk, B. Philosophical Foundations of Clinical Ethics: A Hermeneutic Perspective. 2010. In *Clinical Ethics Consultation Theories and Methods, Implementation, Evaluation*. Ashgate Publishing, UK: 37-51.
- van Willigenburg, T., Verweij, M., Kleemans, C.H.M., Kloot-Meijburg, van der H.H. (1991). *Ethiek, levensbeschouwing en het management in instellingen voor intramurale gezondheidszorg*. Nationaal Ziekenhuisinstituut, Utrecht, 109-110.

Chapter 4



Need for ethics support in Health Care Institutions: views of Dutch board members and ethics support staff

L. Dauwerse, T.A. Abma, B. Molewijk, G. Widdershoven.
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ABSTRACT

The purpose of this article is to investigate the need for ethics support in Dutch healthcare institutions in order to understand why ethics support is often not used in practice and which factors are relevant in this context. This study had a mixed methods design integrating quantitative and qualitative research methods. Two survey questionnaires, two focus groups and 17 interviews were conducted among board members and ethics support staff in Dutch healthcare institutions. Most respondents see a need for ethics support. This need is related to the complexity of contemporary healthcare, the contribution of ethics support to the core business of the organization and to the surplus value of paying structural attention to ethical issues. The need for ethics support is, however, not unconditional. Reasons for a lacking need include: aversion of innovations, negative associations with the notion of ethics support service, and organizational factors like resources and setting. So, there is a conditioned need for ethics support in Dutch healthcare institutions. The promotion of ethics support in healthcare can be fostered by focusing on formats which fit the needs of (practitioners in) healthcare institutions. The emphasis should be on creating a (culture of) dialogue about the complex situations which emerge daily in contemporary healthcare practice.

INTRODUCTION

Clinical ethics is an emerging field, including various means of ethics support, such as ethics committees, ethics consultants and moral case deliberation. Our working definition of clinical ethics support is: a functionary group or body which is explicitly involved in (the organisation of) ethics in healthcare institutions. The literature describes methods of ethics support¹⁻³ and characteristics of ethics support, like access and workload.⁴⁻⁷ Implicitly, this literature presupposes that there is a need for ethics support. Some studies report empirical findings about the need for ethics support.⁸⁻¹⁰ For example, 89% of the UK trust respondents were in favour of ethics support and 87% of British hospital CEC chairpersons expressed a need for ethics support.⁹ In Canada, 95% of the healthcare providers believed ethics support would answer a need.

The need for ethics support is related to the complex, value-laden nature of clinical decision making, the pluralistic societal context and economic constraints.¹¹⁻¹³ However, there is little empirical evidence available about underlying reasons for the need for ethics support. Many of the previous studies did not systematically study why there is a need for ethics support. Moreover, ethics support such as ethics committees are not often consulted in practice. They receive a limited number of cases per year⁹ or meet rarely (24% of committees in Canada reported that they only met six or fewer times a year), probably because they have an inactive agenda or are still trying to identify how they can be effective.¹⁴ Also, ethics consultation services (ECS) have a low number of consultations (22% of the ECS in US-Hospitals performed no consultations in 2006, 90% performed fewer than 25).⁴

The aim of the present paper is to investigate the need for ethics support of Dutch healthcare institutions and to understand which factors are relevant in explaining the presence or absence of such need. We used a mixed methods design, including two survey questionnaires, two focus groups and 17 interviews. This article focuses on the perspectives of board members and ethics support in Dutch healthcare institutions. The assumption is that they have a key role in facilitating and practically organising ethics support, and are only willing to facilitate ethics support if they see an intrinsic need for it.^{15, 16}

METHODS

Design

Quantitative and qualitative methods were used in a mixed methods design.^{17, 18} The mixed methods design was chosen as it enabled us to collect a broad array of quantitative information on the need for ethics support and helped to gain qualitative information about the reasons for such (lacking) need. First, two survey questionnaires with closed and open questions were used to assess the need for ethics support and to explore underlying motivations. The first was addressed at board members as they have an important role in facilitating ethics support. The second questionnaire was directed at ethics support staff, as they have an important role in the actual organisation and implementation of ethics support in the institution. The data of questionnaires

1 and 2 were analysed with SPSS 15 for the closed questions and a thematic content analysis of the open ended questions. This means that themes were constructed from the

data set. The answers to open questions were read line by line and labelled, compared and then clustered into themes. After reordering them several times, we came to the current categorisation: three pros and three cons.

Second, the analyses of questionnaire 1 were used as input for two focus groups in order to validate and further discuss the themes. Third, during the whole research process we conducted interviews (n=17) to discover personal opinions and experiences with ethics support and the need for it.

Setting

All Dutch healthcare institutions (N=2137) received the first survey questionnaire, directed at the board. Board members (BM) were not specified, assuming that BM would be able to assess themselves which member was most appropriate to respond to the questionnaire. The questionnaire identified the function of the respondent; therefore we know which BM responded. Various settings were included: hospitals, institutions for people with an intellectual disability, mental health care institutions, and institutional care of older people. The second questionnaire was directed at ethics support staff, meaning people with expert knowledge for example, chairs of ethical committees or spiritual caregivers involved in organising, implementing or executing ethics support. There is difference in number (638 respondents of questionnaire 1 vs 515 designated ethics support staff members) because not all respondents of questionnaire 1 designated a best informant. Table 1 shows that 62% of the respondents of questionnaire 1 and 55% of questionnaire 2 were from institutions involved in the care of older people. Equally, representatives from a variety of settings participated in the focus groups and interviews.

Procedures

Questionnaire 1 was developed by reading literature, talking to experts (n=7) from different sectors and testing the questionnaire with BM and experts (n=9) from different sectors. Participants of the pilot indicated that our questionnaire was too long and that questions couldn't be answered by BM. We searched for ways to get as much information as possible in a short questionnaire. The main topics we wanted to ask the BM were included in the short questionnaire of Slowther.⁸ We added open ended questions about the goals of ethics support, the desirability of ethics support and existing support mechanisms. An additional advantage of using Slowther's⁸ questionnaire was that we were able to do an international comparison.

This (postal) questionnaire was sent to all Dutch intramural healthcare institutions, listed at the Dutch Ministry of Health Welfare and Sports. The data collection phase took place between April and July 2008, including two reminders and a telephone follow-up. During the telephone follow-up it turned out that the 2137 individual healthcare institutions were part of 864 unique legal bodies. These are umbrella organisations with a legal status. Hence, there are two response rates of this first questionnaire, namely 30% (638/2137) at the level of individual institutions and 56% (485/864) at the level of unique legal bodies.

Questionnaire 2 was also developed by reading literature and conversations with experts (n=12) from different sectors. These were for example persons with methodological

experience in (digital) surveys and persons with substantial knowledge of ethics support. This questionnaire was tested with 12 (other) experts from different fields, who completed the questionnaire and gave feedback by email. This digital questionnaire included the questions BM were unable to answer in the pilot and the questions focused on specific ways of ethics support, and covered themes like content, participants, integration and evaluation of ethics support.

This digital questionnaire was sent to all ethics support staff members which were designated by the respondents of questionnaire 1. The data collection took place between April 2009 and July 2009, including two reminders and a telephone follow up. The response rate of this second questionnaire is 48% (247/515).

We organised two focus groups with persons who had answered the questionnaires (summer 2009); both groups had a mixed composition of BM and ethics support staff (totaling 22 participants). The focus groups took two hours each. The participants received a report of the analysis of the two questionnaires. The dialogue focused on the need for ethics support, goals of ethics support and (in) formal ways of ethics support. The participants received the summary (member check) of the meeting and their (sometimes extended) reactions and comments were integrated in the analysis.

Furthermore, we conducted interviews (n=17) during the whole research process. First, inventory interviews with pioneers in the field of clinical ethics to explore the national field (n=6). Second, in-depth interviews with best informants and BM with an established ethics support service in their organisation to understand how ethics support works in practice (n=7). Third, open interviews with (international) experts in the field of clinical ethics to mirror the Dutch findings to the international context (n=4). Themes included the need for, goals of and (in)formal ways of ethics support.

Analysis

The data were analysed separately and then transformed for further analysis and comparison (cross over track analysis).¹⁸ This means that questionnaires 1, 2, the interviews and focus group were initially analysed separately. A second step in the analysis was to compare the themes found in the first analyses with each other. The closed questions were analysed by using Microsoft Excel and SPSS 15. This entailed a descriptive analysis including frequencies, cross tabs and graphs. Subsequently, a thematic content analysis was used for the answers to the open ended questions in the questionnaires, and the transcripts of the interviews and the focus groups. We followed an open coding process by reading the qualitative material line by line and labelling them with (sub)themes. Next, the themes were connected and clustered and sometimes relabelled. Finally, relations were visualised in a mind map and discussed within the research team, within a meeting of the advisory committee and within the focus groups. The interviews were analysed continuously, following the findings, searching for corroboration and deeper understanding.

Table 1: Participating healthcare settings

Setting/ respondents	Questionnaire 1 ¹				Questionnaire 2			
	n	%	N	%	n	%	N	%
Care of older people	397	62%	1660	78%	135	55%	308	60%
Mentally disables	78	12%	186	9%	30	12%	72	14%
Hospitals	99	16%	171	8%	48	19%	82	16%
Mental health	64	10%	120	6%	19	8%	46	9%
Other ²	-	-	-	-	15	6%	7	1%
Total	638	100%	2137	100%	247	100%	515	100%

FINDINGS

Respondents

Respondents of questionnaire 1 (figure 1) were mainly board members (BM) or directors (68%). Other respondents belonged to the middle management (21%), the general staff (6%), were ethics support staff (4%) or healthcare providers (1%). Examples are, respectively: location manager, policy adviser, member ethics committee and nursing home physician. Respondents of questionnaire 2 (figure 2) were mainly ethics support staff (49%), such as a member of an ethics committee, facilitator of moral case deliberation, ethics consultant. Other respondents were BM/director (18%), middle management (17%), general staff (12%) or healthcare provider (4%). Ethics support staff sometimes combine functions for instance, being ethics support staff and healthcare provider, or ethics support staff and general staff.

¹ BM = Board member, BI = Best informant, FG = focus group

² Questionnaire 1 doesn't have an 'other' option because the sector was given in the address list we used. In questionnaire 2 we asked for the sector and then it turned out that also other settings responded, including: youth care, institutions for sensory or physical handicapped people, social service and support for people with inquired brain injury.

Figure 1 'Respondents' questionnaire 1.

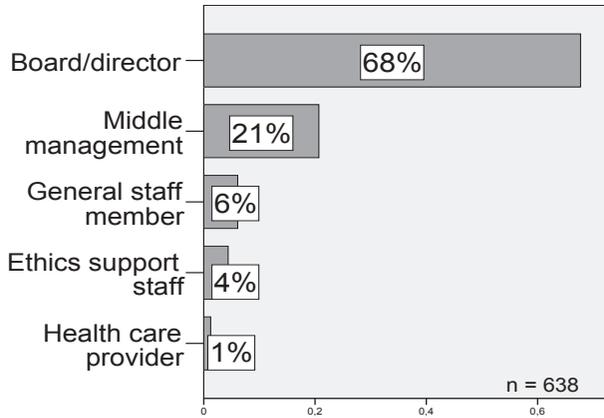
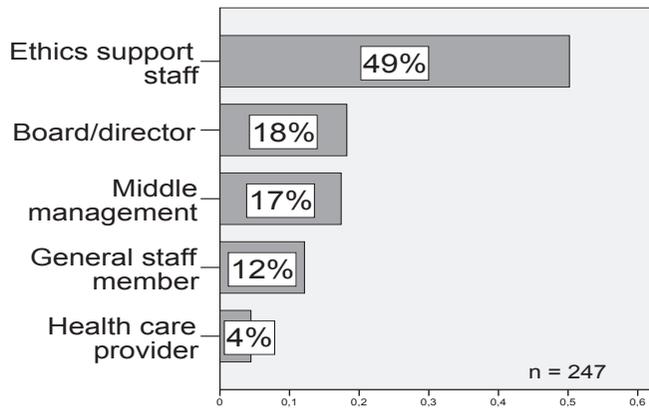


Figure 2 'Respondents' questionnaire two.



Need for ethics support

Sixty eight per cent of BM (questionnaire 1) agree that ethics support is desirable. In the answers to the open questions, three relevant factors emerge: the complexity of contemporary healthcare, the contribution to the core business of the healthcare institution, and the need for structural attention to ethical issues (table 2).

Table 2: Does institution miss ethics support when it is not present?

	Not present	Not present & missing it	Not present & not missing it
Ethics committee	49% (122/ 247)	32% (38/ 118)	68% (80/ 118)
Moral deliberation	56% (138/ 247)	43% (57/ 132)	57% (75/ 132)
Ethics consultant	85% (211/ 247)	18% (37/ 202)	82% (165 / 202)

Complexity of contemporary healthcare

A first explanation for the need for ethics support refers to the complexity of contemporary healthcare. Responses to questionnaire 1, for example, indicate that the ageing population and the empowerment of care receivers (patients and their families) require ethics support: ‘Care questions are complex, people empowered and family more explicitly manifests themselves’. Respondents see ethics as an inherent part of contemporary healthcare processes and indicate that ethics is not limited to medical ethical issues like euthanasia. Questionnaire 2 reinforces these findings: ‘Cardiologists, nurses, patient and family often look from a different angle to a patient with heart failure. Hence, communication is confusing. Therefore moral case deliberation is a challenge for us now.’ Sometimes respondents refer to their setting for example, mentioning that in mental health care there are many ethical questions. Participants in the focus groups stress that ethics support should not only be used as a way to legitimise, but that it should be visible in daily activities and integrated in all veins of the organisation. Interviewees express a need for participation of all stakeholders in ethics support, including care receivers (patients, family members) and health insurers.

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Contribution to the core business of the institution

A second explanation for the need for ethics support is its contribution to the core business of the organisation. Questionnaire 1, for example, shows that a multidimensional approach to ethical dilemmas is deemed to contribute to awareness and quality of care: ‘It is important to consider ethical problems from several points of view and translate results into policy’ and: ‘This (ethics support) strengthens the position of employees and the quality of care for clients’.

Questionnaire 2 shows that an ethics committee may provide a structure for addressing ethical issues, an ethics consultant may help with agenda setting and moral case deliberation may increase reciprocal understanding: ‘It would be valuable to do this (moral case deliberation) together in order to know each other’s vision and come to a more shared vision’.

In the focus groups these findings are confirmed. Participants agree that ethics support, such as, moral deliberation, may stimulate a (pro)active attitude towards ethical issues. An interviewee mentions that ethics support can be an important facet of policy, on the same height as finances, material conditions and personnel.

Need for structural attention to ethical issues

A third explanation for the need for ethics support is that it provides structural attention to ethical issues. Although existing, more informal, ways of ethics support are considered important, regular and structured ways of attention for questions about good care can have an added value. Often, there is little or only ad hoc attention for ethical questions and therefore ethical aspects stay implicit: ‘Daily activities offer little room to experience a structured exchange of views on ethical issues’ (questionnaire 1).

Questionnaire 2 illustrates that ethical questions should be more explicit in order to enable reflection: ‘In daily practice there are many ethical dilemmas which are not made explicit nor is there reflection about it’.

Participants of the focus groups agree that structure is important, because it makes ethical issues visible and enables moral learning. Interviewees explain that structural ethics support diminishes ad hoc solutions and fosters effectiveness: ‘Some people tend to be more able to make ethical aspects visible than others and that determines group effectiveness. So, then (if there is no ethics support) it is a matter of chance whether a group is effective or not.’ (Director, mental health care).

No need for ethics support

The previous paragraph showed that many healthcare institutions experience a need for ethics support. Yet 32% of the BM disagree with the statement that ethics support is desirable in their institution (questionnaire 1). Specific kinds of ethics support are not deemed necessary (questionnaire 2). A considerable number of respondents say that their institution does not have an ethics committee (49%), moral case deliberation (56%) or an ethics consultant (85%), and, moreover, many report that ethics support is not being missed. For example, 68% of respondents say not to miss an ethics committee (table 2).

Aversion of innovations

The qualitative findings of questionnaire 1 show specific ways of ethics support are not missed, because there is an aversion for innovations and current ways are enough: ‘Of course this should be organised when necessary, but we have enough expertise and do not want ‘another’ separate service’, ‘Ethical/moral consideration should be a part of regular contact moments like multidisciplinary team meeting or discussion of progress’, ‘Informal contacts with spiritual counsellor and psychologist is enough’.

These may include both formal and informal forms of ethics support. Respondents refer to the consultation function of psychologists, pastoral care workers and other staff members as well as to management team meetings and multidisciplinary team meetings as alternatives for (formal) ethics support. Furthermore, questionnaire 2 illustrates that ethics support is not seen as requiring a separate meeting: ‘Existing moral case deliberation is not seen as a separate meeting but is interwoven with the development of the treatment plan’. The focus groups and interviews confirm that informal ways of ethics support are important.

Negative associations with the notion of ethics support

BM and ethics support staff refer to negative associations with the notion of ethics support as explanation for the absence of need. Respondents to questionnaire 1 mention there is no need for a separate service but for integral responsibility because professionals should always ask themselves what is good in a specific situation: ‘Another isolated service: nonsense! Ethics should be in the whole capillary system of the organisation and not isolated. An ethics support service would be too much distance from work floor.’

Respondents to questionnaire 2 stress that a separate service for ethics is problematic and they note that ethics committees are distant from practice: ‘Access to the committee is not found easily by employees and employees have the image that an ethics committee is fairly heavy’.

In the focus groups this is affirmed; participants notice that the word ethics support ‘service’ does not fit to the Dutch context because of its connotation with a formal body having a high threshold. It is also mentioned that the words ‘ethics’ and ‘moral’ have a negative association for many healthcare providers. An interviewee illustrates this negative association with ethics, by referring to an ethicist who was unable to talk in ‘normal’ language. ‘Within the previous committee there was an ethicist and no matter how she tried, she didn’t succeed in transferring in normal language, even to physicians. After that education you easily end up in that. They always think in terms like autonomy and these are so theoretical that you do not reach the people you want to.’ (Ethics committee member, institution of older persons)

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Organisational factors

Organisational factors may also explain the lack of a need for ethics support. Respondents of questionnaire 1 mention resources, size and setting as explanations: ‘Within our care home [for older people] ethical issues in general are less complex and more incidental than in, for example, hospitals’.

Respondents notice that some institutions have other priorities than ethics support, smaller institutions may less need ethics support than large institutions, and care of older people may have ‘easier’ questions which may not require ethics support. A few respondents indicate that they do not have ethical questions (daily) or that ethics support is not needed because everything is clear given the spiritual background of the organisation. Questionnaire 2 suggests that care institutions for older people often are small, which might imply a link between size and sector. Participants in the focus groups suggest that an institution with a business-like approach to healthcare, will probably not invest in ethics support. An interviewee mentions that an institution may experience a need for ethics support, but not have the resources to facilitate it: ‘The board says: of course it is important to talk about ethical issues, but we do not have the means for it. While it should be facilitated by the board, you cannot only leave it to managers or employees.’ (Board secretary, mental health care).

DISCUSSION

Our study contributes to the field of clinical ethics by providing a robust evaluation of the need for clinical ethics support in Dutch healthcare and the potential barriers to its development. While previous studies report a high prevalent need for ethics support⁸⁻¹⁰ our findings show that the need for ethics support cannot simply be assumed. In the Netherlands, two thirds of board members see a need for ethics support. However, one third of the responding board members see no need for ethics support in their institution.

Respondents who see a need for ethics support, tend to view this as an inherent part of care, enabling the institution to deal with complexity. They seem to regard ethics support as a natural development within their institution.¹⁹ Mechanistic structures and top down ways of solving ethical issues are regarded as non-desirable in the Dutch context. Deliberation-based ethics²⁰ in which there is room for negotiation about what's good in a specific situation, is preferred over advice-based ethics in which an ethicists says what's the best thing to do.

Our findings illustrate that in the Netherlands ethics support is used for creating a (culture of) dialogue on the complex issues which arise daily. Instead of an emphasis on financial or legal considerations, ethics support is used to promote core values of (practitioners within) the organisation. These healthcare institutions which are in favour of ethics support focus on creating structural ethics support as a reaction on the current culture of control¹⁹⁻²¹ which is, for example, characterised by management of output and bureaucratic quality assurance procedures.

Our respondents were quite articulate about the type of ethics support they wanted or not. An additional 'service' in terms of another institutional body or function was seen as undesirable. Related to this is the finding that certain concepts in relation to clinical ethics are confusing. The international literature uses the term ethics support service, but this term is not useful in the Dutch context because the word service has another meaning (unit, ward). Therefore, we decided to use the term 'ethics support' instead of 'ethics support service' in the second questionnaire, focus groups and interviews. Furthermore we explicitly defined within the questionnaires our working definition of three possible formats of clinical ethics support: ethics committees, moral deliberation and ethics consultant. In the second questionnaire we checked with the respondents if they worked with the same definitions and a majority affirmed our definitions.

Since admitting a need for ethics support or denying it also depends on the goals associated with such support, we recommend further research on the goals of ethics support as seen by healthcare institutions. Since various parties have different perspectives on ethics support, we would recommend investigating the needs of stakeholders other than board members and ethics support staff. For instance, the needs of care providers (including physicians, nurses and other professionals) and recipients of care (patients and families) within the institution. Likewise, it would be relevant to know the needs for ethics support envisaged by parties outside the institution, such as national policy makers, healthcare insurance companies and professional and patient organisations.

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REFERENCES

1. Molewijk B, Abma T, Stolper M, et al. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *J Med Ethics* 2008;34:120e4.
2. Manschot H, Van Dartel H, eds. In gesprek over goede zorg. Overlegmethoden voor ethiek in de praktijk (Being engaged in conversation on good care. Conversation methods for ethics in practice). Amsterdam: Boom, 2003.
3. Steinkamp N, Gordijn B. Ethical case deliberation on the ward. A comparison of four methods. *Med Health Care and Philos* 2003;6:235e46.
4. Fox E, Myers S, Pearlman R. Ethics consultation in United States Hospitals: a national survey. *Am J Bioeth* 2007;7:13e25.
5. Meulenbergs T, Vermeylen J, Schotsmans PT. The current state of clinical ethics and healthcare ethics committees in Belgium. *J Med Ethics* 2005;31:318e21.
6. Hurst S, Reiter Theil S, Perrier A, et al. Physicians access to ethics support services in four European Countries. *Health Care Anal* 2007;15:321e35.
7. Pedersen R, Akre V, Førde R. What is happening during case deliberations in clinical ethics committees? a pilot study *J Med Ethics* 2009;35:147e52.
8. Slowther A, Bunch C, Woolnough B, et al. Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. *J Med Ethics* 2001;27:2e8.
9. Whitehead JM, Sokol DK, Bowman D, et al. Consultation activities of clinical ethics committees in the United Kingdom: an empirical study and wake-up call. *Post grad med* 2009;85:451e4.
10. Racine E, Hayes K. The need for a clinical ethics service and its goals in a community healthcare service centre: a survey. *J Med Ethics* 2005;32:564e6.
11. Aulisio M, Arnold R. Role of ethics Committee. Helping to address value conflicts or uncertainties. *Chest* 2008;134:417e24.
12. Reiter-Theil S. Ethics consultation on demand: concepts, practical experiences and a case study. *J Med Ethics* 2000;26:198e203.
13. Aulisio MP. Meeting the need, ethics consultation in health care today. In: Aulisio MP, Arnold RM, Youngner SJ, eds. *Ethics consultation from theory to practice*. Baltimore, Maryland: The Johns Hopkins University Press, 2003:3e22.
14. Gaudine A, Thorne L, LeFort SM. Evolution of hospital clinical ethics committees in Canada. *J Med Ethics* 2010;36:132e7.
15. Slowther A. Ethics Consultation and Ethics Committees. In: Ashcroft RE, Dawson A, Draper H, Mcmillan J, eds. *Principles of Health Care Ethics*. John Wiley & Sons, Ltd, Chichester, UK, 2007:527e34.
16. Bloemhof A. Bezielde besturen. Directeuren en bestuurders in de zorg over de winst van ethische reflectie en moreel beraad. (Impassioned management. Health care directors and board members about the surplus value of ethical reflection and moral deliberation). Amsterdam: Communicatie Company, 2008.
17. Greene JC. *Mixed Methods in Social Inquiry*. San Francisco: Wiley & Sons, 2007.
18. Mertens DM. *Research and evaluation in Education and Psychology. Integrating Diversity with quantitative, qualitative and mixed methods*. Thousand Oaks, California: Sage publications, 2010.

19. Jones GR. Types and Forms of Organizational Change, in: *Organizational Theory, Design and Change*. Upper Saddle River, New Jersey 5th edition: Prentice Hall, 2006:301e33.
20. Widdershoven G, Abma T, Molewijk B. Empirical ethics as a dialogical practice. *Oxford Blackwell Publishing. Bioethics* 2009;23(4):236e48.
21. Weick KE. Management of organizational change among loosely coupled elements. In: Weick KE, eds. *Making sense of the organization*. Malden: Blackwell Publishing, 2006:380e401.

Chapter 5



Goals of clinical ethics support. Perceptions of Dutch Health Care Institutions

ABSTRACT

In previous literature, ethicists mention several goals of ethics support. It is unknown what key persons in healthcare institutions see as main- and sub-goals of ethics support. This article presents the goals of ethics support as perceived by the board members and members of ethics support staff. This is part of a Dutch national research using a mixed methods design with questionnaires, focus-groups and interviews. Quantitative and qualitative data were analyzed and combined in an iterative process. Four main clusters of goals were found: 1) encouraging an ethical climate, 2) fostering an accountable and transparent organization, 3) developing professionalism and a final goal, overarching the previous three, 4) good care. Most important sub-goals of ethics support were: attention for ethical issues, raising awareness of ethical issues, fostering ethical reflection and supporting employees. The article ends with a discussion on the desirability to further operationalize the general goal of good care, the context-boundedness of our findings and the need to relate goals of ethics support to the features of organizational cultures to further improve the integration of ethics support in healthcare institutions.

Key words: Organizational Objectives, Clinical Ethics, Quality of Health Care, Mixed Methods Research

INTRODUCTION

Previous literature shows that healthcare institutions increasingly acknowledge the value of ethics support, and structurally integrate clinical ethics in their organization through ethics support ranging from ethics consultation and ethics committees to moral case deliberation (Fox et al., 2007; Slowther et al., 2002; Slowther, 2007; Dauwerse et al., 2011). At the same time, the goals of ethics support are often not, or not clearly, formulated in practice. Slowther (2007) indicates that the aims of ethics support are often cast in general terms like ‘improving patient care.’ In her view, this is remarkable as the legitimacy of ethics support within healthcare institutions and society as a whole depends, among other things, on a clear formulation of its goals (Slowther, 2007).

The international literature reveals a broad set of goals to be realized by ethics support. In different wordings scholars emphasize that ethics support should ultimately enhance the quality and goodness of care. For example, according to the ASBH-report (1998, p. 8) the general goal of health care ethics consultation is to “improve the provision of health care and its outcome through the identification, analysis and resolution of ethical issues as they emerge in clinical cases in health care institutions.” Aulisio et. al (2000), for instance, indicate that ethics consultation aims to ‘to help to identify and analyze the nature of the value conflict or uncertainty’ (p.61) and to ‘forge consensus among involved parties.’ More specifically authors stress that information exchange, communication, shared understanding and decision-making are goals of ethics support (Racine et al., 2006; Reiter-Theil, 2001). Others emphasize the importance of moral reflection as a goal of ethics support (Svantesson et al., 2007; Van Laere et. al., 2009; Molewijk et. al, 2008; Abma et. al, 2009). Reflection includes reflection on a case, reflection on what it means to be a good professional and reflection on institutional or organizational issues.

While ethicists specify goals of ethics support, it is largely unknown what kind of goals key-persons in healthcare institutions strive for when implementing ethics support. Some empirical studies cast light on the goals seen as important in practice. For instance, findings of a survey of Fox et al. (2007) show that intervening to protect patients rights (94%), resolving real or imagined conflicts (77%), changing patient care to improve quality (75%) and increasing patient / family satisfaction (68%) were regarded as important goals of ethics support by US hospitals. Molewijk et al. (2008) present the results of a study in which participants of moral case deliberation stated what they perceived as goals of moral deliberation. From a list of 15 different goals, the following goals were reported as most important: 1) to activate my job motivation, 2) to get knowledge of and insight in moral issues, 3) to pay attention to reasons and arguments and 4) to improve mutual understanding. Both these studies reveal important insights, but used a preordained questionnaire, which may have steered the answers.

The purpose of this article is to present results of a systematic, empirical research on what key-persons in Dutch healthcare institutions consider as goals of ethics support. We started with open ended questions for board members of all Dutch healthcare institutions as this allowed them present *their* goals. The presumption is that a better understanding of the goals of ethics support in practice may help ethicists to be more aware of the organizational context in which they operate, and provide a tool to foster a dialogue about the goals of

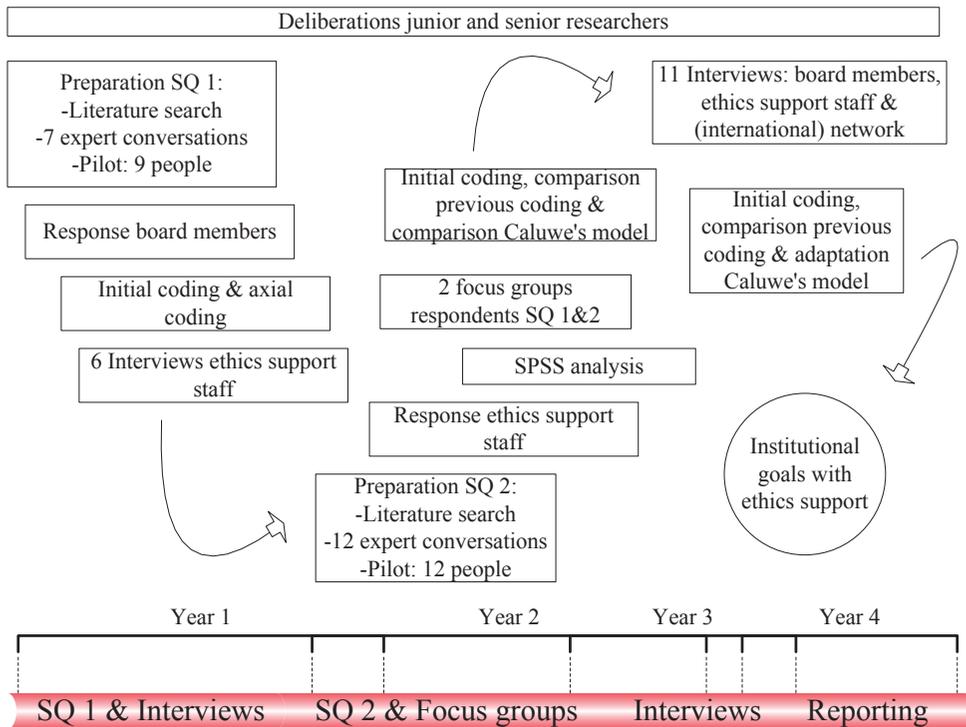
ethics support among ethicists and practitioners in order to improve the implementation and evaluation of ethics support.

METHODS

This investigation was part of a larger research project in which we used an integrated mixed methods design. Quantitative and qualitative methods were intentionally mingled during the research process for purposes of triangulation and complementarity (Mertens, 2010). Research subjects were board members of all Dutch health care institutions, ethics support staff, indicated by the replying board member, and (inter) national advocates of ethics support. Ethics support staff refers to employees of a health care institution who organize and implement ethics support (such as chairs of ethical committees, or spiritual caregivers).

Figure 1 presents a detailed description of the research procedures followed.

Fig. 1 Research flow: data collection and analysis



Survey questionnaire 1 (SQ1) was directed at the board members of healthcare institutions. Its development has been described elsewhere in detail (Dauwerse, et al. 2011). The main topics of the survey questionnaire were based on the short questionnaire of Slowther (2001), pointing at needs and ways of ethics support. Among other things we added an open-

ended question on the goals of ethics support. This (postal) questionnaire was sent to all intramural healthcare institutions (N = 2137) registered with the Netherlands Ministry of Health, Welfare and Sports, including elderly care institutions, hospitals, mental healthcare and institutions for the mentally disabled. The response rate was 56%. A possible reason for not answering SQ 1 is that the postal questionnaire did not reach the right person as we did not have names of the board members. Furthermore, ethics support might not have the priority of board members. After the first analysis of questionnaire 1, we conducted 6 semi-structured interviews with ethics support staff members to further understand the initial analysis of questionnaire one including the first analysis of the goals and to prepare survey questionnaire 2. Respondents were selected by a national platform for ethics support. The interviews were recorded, analyzed, and returned for validation (member check).

Survey Questionnaire 2 (SQ2) included questions that the board members were unable to answer in the pilot e.g. on content, participants, integration and evaluation of ethics support. The relationship between SQ1 and SQ2 was that they both investigated the need for, ways of and goals of ethics support in Dutch Health Care institutions. Different were the respondents (board members in SQ 1, ethics support staff in SQ 2), number of questions (more in SQ2) and the way of asking (open versus closed questions). For example, in SQ2, questions about the goals of ethics support were closed; the answering options were based on the first analysis of the responses to the open ended question about goals of ethics support in questionnaire 1. This (digital) questionnaire was sent to ethics support staff, indicated in the response to SQ1 (N = 515). The response rate was 48% (247 / 515). A reason for not answering SQ 2 might be that the questionnaire was too long and respondents did not have enough time to complete it.

In addition two heterogeneous focus groups were organized. They were attended by a mix of board members/directors and ethics support staff. We constructed the focus groups with board members and ethics support staff because they are well informed and reflective. Further, our research also aimed to stimulate dialogue about ethics support with this target group on a national level as these respondents play an important role in facilitating and organizing ethics support. Participants received a mid-term report on the research prior to the meeting. The meeting itself was structured by the issues emerging from the survey questionnaires, and followed an agenda that left ample room for exploration and dialogue. Each two-hour session was moderated by the first and the last author. The conversations of the two focus groups were summarized and sent to the participants for validation (member check).

Aiming for corroboration and deeper understanding of the findings we conducted 11 additional semi-structured interviews in the third year of the overall research project. Themes again included goals of healthcare institutions concerning ethics support, needs for ethics support, and forms of ethics support. The interviews were recorded, analyzed, and returned for validation (member check).

Analysis

The data were first analyzed separately and then transformed for further analysis and comparison (crossover track analysis) (Greene, 2007). The analysis of the qualitative data

on goals of ethics support followed a thematic content analysis. There was an initial coding of the data in which we read each text part line by line and labelled it with codes. The codes of all data were then compared and clustered and renamed into new codes that covered all initial codes. In this phase we also made a detailed description of the initial codes. Then, we searched for relationships among the codes and visualised this in a first model (which finally led to figure 2). This model was discussed between the researchers in order to find the most appropriate codes/labels and clustering of the goals for ethics support. After incorporating their response these codes were used for the closed question about goals of ethics support in SQ2. The answers to the *closed* questions of SQ 2 were analyzed using SPSS 15. The analysis was completed by the first author together with the research team. The combination of methods (triangulation procedure) added breadth to the study, and the qualitative data provided explanations for the numeric data from the surveys.

RESULTS

Respondents listed a very broad array of goals of ethics support in SQ1. In total we identified four main goals and eight sub-goals. Table 1 summarizes how ethics support staff (SQ2) valued different sub-goals of ethics support.¹ The answering categories were based on the initial analysis of the responses to SQ1. Therefore they are not exactly the same as figure 2, which is the result of a more rigorous analysis. Respondents of SQ2 characterized the importance of each goal by indicating the goal as: ‘(absolutely) a goal’ or ‘(absolutely) no goal.’

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Table 1: Reported sub-goals of ethics support staff with CES (SQ2, n = 86)

Goals	(Absolutely) a goal	(Absolutely) no goal	No answer
Attention for ethical issues	98%	2%	0%
Raising awareness of ethical aspects	97%	3%	0%
Fostering ethical reflection	95%	5%	0%
Supporting employees	92%	6%	2%
Systematic deliberation on ethical issues	84%	14%	2%
To promote decisions with an ethical dimension	81%	14%	5%
To advice about ethical issues	78%	17%	5%
To make ethical policy	72%	26%	2%

1 There are no data available of how the board members valued the importance of the different goals since the categories were not identified at that time.

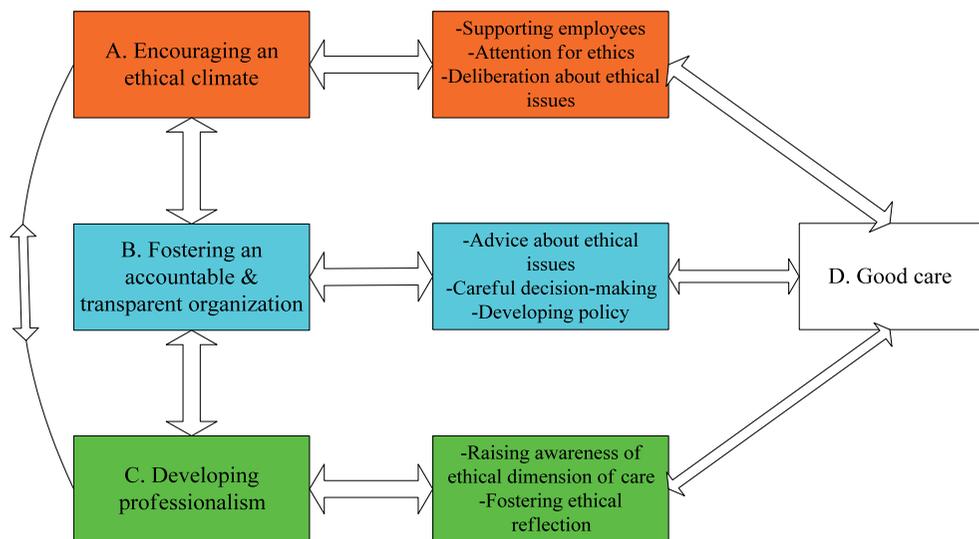
Table 1 shows that respondents of SQ 2 state that all sub-goals of ethics support in healthcare institutions are important. At least 72% the respondents indicate each sub-goals as (absolutely) a goal.

The goals that were most often mentioned as important were: attention for ethical issues (98%), raising awareness of ethical aspects (97%), fostering ethical reflection (95%), improving quality of care (93%) and supporting employees (92%).

Respectively 17% and 26% of the ethics support staff indicated that 'to advice about ethical issues' and 'to make ethical policy' should (absolutely) not be a goal of clinical ethics support.

The broad set of goals was clustered into a framework including four main goals of ethics support (see figure 2): a) Encouraging an ethical climate (including), b) Fostering an accountable and transparent organization, c) Developing professionalism and d) Good care.

Fig. 2 Reported goals of health care institutions with Clinical Ethics Support



Encouraging an ethical climate

Key-persons in healthcare institutions see structural ethics support as a vehicle to encourage an ethical climate within the organization. This entails creating an environment in which reflection on ethical issues is stimulated. This implies that ethics is a part of the organizational culture, as an everyday issue. Ethics support facilitates an ethical climate by: 1) attention for ethics; 2) supporting employees and 3) deliberation about ethical issues.

Attention for ethics

Encouraging an ethical climate includes attention for ethics. Attention for ethics was considered as a very important goal of ethics support among a large part of the respondent

(98%). Healthcare institutions see ethics support as a means to pay attention to ethical issues continuously. *“Make [employees] enthusiastic about ethical dilemmas.” (Respondent SQ1)* and *“Disseminate ethics broadly.” (Respondent SQ1)*

Supporting employees

Employees have to deal with moral questions daily, and healthcare institutions see ethics support as a means to cope with these questions by providing specific methods and knowledge. Supporting employees is considered a highly important goal of ethics support among the respondents (92%). It is acknowledged that especially employees on the work-floor are often in a difficult position and need support to be able to handle moral dilemmas. The perceived surplus value of ethics support varies from stimulating an enhanced understanding of cases in daily practice to improving the satisfaction and comfort of employees:

“A feeling of safety and the satisfaction of employees, both physicians and nurses. For me that’s a very important outcome” (Interviewee, Director knowledge centre, mental health care)

Deliberation about ethical issues

Health care institutions see ethics support as a means to facilitate deliberation about ethical issues in daily practice. Respondents indicate that ethics support should initiate or facilitate (systematic) conversation about ethical issues in the organization; to create an *“Opportunity to talk about choices and dilemmas in our work.” (Respondent SQ1)* This implies that there is an open dialogue between all stakeholders, characterized by equality and asking questions, in order to understand the perspectives of the other. Through deliberation, ethical issues become a part of the organizational culture: *“To promote a climate in our residence in which it is possible to talk about ethical issues.” (Respondent, SQ1)* Addressing ethical issues should be an everyday activity: *“It [moral deliberation] is just a tool for conversation” (Moral deliberation conversation leader, mental health care)*. Deliberation is regarded as a means to make the organization work on a dialogical basis.

‘Influencing processes and relationships so people are able to talk with the client or family, but also to have dialogues with each other (network organization elderly care institutions)’

Fostering an accountable and transparent organization

Healthcare institutions use ethics support to foster an accountable and transparent organization. This means that ethics support is seen as a vehicle to express and (re)shape their accountability. Ethics support can help health care institutions to be an accountable organization by developing and implementing an institutional policy (including core values of the organization). Respondents mention the following sub-goals: 1) Careful decision-making; 2) Advice about ethical issues and 3) Developing policy.

Careful decision-making

Respondents indicate that within an accountable organization stakeholders are able to make careful and justified decisions concerning ethical issues. Ethics support is considered as a vehicle to realize the goal of careful decision-making. For example:

“We need to take responsibility for the choices we make. Choices in treatment techniques or diagnostic activities. Or: what kind of patients do we particularly want to treat here? These kinds of choices should be based on argumentation. In my view an ethical discussion about this, is an important contribution to these arguments.” (interviewee, chair of the board, hospital)

This implies that ethics support facilitates stakeholders to motivate and take responsibility for their actions, and to be accountable for actions. Ethics support stimulates practitioners to develop and express their professional accountability regarding their decisions, actions and viewpoints.

Advice about ethical issues

This means that an expert gives advice (asked and unasked) on ethical issues which arise in daily practice. Advice can be either general, or focus on concrete cases. The quantitative data show that advice is not univocally considered as an important goal of ethics support. The qualitative data explain that advice has benefits in terms of leading to a shared perspective and/or solution of a day-to-day situation:

“Advice can facilitate collaborative suggestions / bring a fast solution. For example a woman with dementia who urinates in her bed. Together you can come to a certain frame, you can look at the situation from different perspectives” (participant FG)

However, respondents indicate that a focus on advice might make ethics support a matter of experts, having a high threshold:

“It will be a product of a small group, with too much focus on principles. It could be a base for reflection and learning but should stimulate professionals to think themselves’ (Participant FG)

Developing and implementing policy (on ethical issues)

Respondents indicate that ethics support can facilitate policymaking within healthcare institutions as it invites stakeholders to express what they see as important (core) values for the organization. Respondents see ethics support as a way to formulate a mission or vision: ‘To develop guidelines and vision’ (Respondent SQ1). More specifically, ethics support can help healthcare institutions to develop policy on how to deal with ethical issues within their organization: “We only have one main goal and that’s the agenda setting of ethics on all units, all levels and within all layers of the organization.” (Interviewee, Medical ethicist

hospital). Ethics support can also help implementing policy throughout the organization. This implies that the vision on quality is diffused within all layers of the organization. Respondents indicate that ethics support connects rules to practice and helps to better apply existing guidelines. For example:

“As organization we think it is important to implement the principle of recovery. It is a challenge because: ‘we, with a small group, might think it is important. But there are about 500-600 people working here for this target group and they all have a practice.’ In order to implement this, we should have dialogue. And than moral deliberation is a method.” (Director knowledge centre, mental health care)

Some respondents indicate that ethical justification is a goal of ethics support. *“Being univocal to the external world.” (Respondent SQ1)* and *“Transparency of ethical issues.” (Respondent SQ1)*

Respondents see policymaking not as one of the more important goals of ethics support. They seem to be a bit sceptical about the instrumental value of ethics support as a vehicle to realize organizational goals as this might decrease the free space for reflection and dialogue. Some respondents consider ethics support as an enclave within the organization that becomes more and more driven by economic values and business concepts. If ethics support is tied up with policy goals and strategic action, they fear that it will lose its free conversation space and communicative action.

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“A cultural change is needed to achieve the goal of deliberation about ethical issues. It should be supported by the whole healthcare institution and the culture should not be too business-like.” (Participant FG).

Developing professionalism

A third main goal of health care institutions with ethics support is developing professionalism. This is an educational goal. It entails that practitioners are able to recognize ethical questions and are able to deal with them. Sub goals of developing professionalism are: 1) Raising awareness of the ethical dimensions of care and 2) Fostering ethical reflection.

Raising awareness of the ethical dimensions of care

Respondents assume ethics support will raise the awareness of the ethical dimensions of care among employees. Awareness of ethical issues gained high priority (97%). Respondents assumed that through ethics support practitioners will increasingly become sensitive for and able to recognize ethical aspects in daily health care practice: *“To improve the capacity of employees to recognize ethical aspects of care.” (Respondent SQ1)*. Another interviewee explains what awareness means in elderly care:

“Most important is the awareness that you (as caregiver) make ethical choices every day. For example: will you tell a daughter of a mother with dementia that she has a relationship with another patient?” (Head of ethics committee, nursing home)

Raising awareness is considered as an extremely important goal of ethics support. This is related to the concern that employees not always recognize their responsibilities concerning the ethical dimensions of their work:

“Each healthcare professional should think about the good and bad of actions. I am worried about ethical reflection of professionals and have the idea they execute what is already decided and documented by others and that the appeal on their own responsibility is decreasing. Professionals have the idea they cannot influence (organizational) choices anymore. Care is, however, about unique people and when there is no appeal on the individual assessment capacity of professionals anymore, than this damages the profession.” (Director of Christian association for health care authorities)

Fostering ethical reflection

Developing professionalism also means stimulating and fostering reflection. This is considered as an extremely important goal of ethics support (95%). This implies that practitioners develop attitudes and skills which make them able to (systematically) reflect upon moral situations and moral questions. Reflection results in looking differently at a situation, for example by asking oneself: ‘*Am I patient enough?*’ Ideally, ethics support should stimulate reflection in daily practice:

“That you, as a matter of fact, develop a routine to think in a concrete situation, but also afterwards: ‘what we did, was it good or should we have acted differently?’” (interviewee, chair of the board, hospital).

One interviewee has an advanced idea of three levels of reflection and states that ethics support facilitates reflection on a deeper level, namely the second and third level.

“There are different levels of reflection. First, very basic, e.g.: ‘My goal is to do all 17 beds before the end of the morning.’ At the end I assess: ‘did I make it?’ No, again there was a lack of time at the end. Why is that? I can reflect on that critically. A second level of reflection asks: ‘is it desirable that I want to reach this goal in this way? Shouldn’t we organize work another way?’ A third, deeper form of reflection is: what does this say about the care we want to offer? The way we deal with it. These levels are also denominated as: primary, secondary and tertiary reflection or single loop, double loop and triple loop learning” (Director of Christian association for health care authorities)

Reflection is considered as an important goal. This is related to the lack of reflection that is signalled in the current healthcare context:

“Employees work in a very hectic environment, that’s unbelievable. Often they don’t have time to reflect on situations. When we are called in, then we do reflect, it is a

moment of reflection, consideration. Like: 'we don't do it that bad' or 'it could be different' or 'it's not strange that I think that' or 'she also has it.' Yes, that's really a surplus value" (interviewee, member of ethics committee, nursing home).

Good care

Good care is the fourth main goal healthcare institutions have with ethics support. They want to deliver care in concordance with the needs of patients, given available means. Participants explain that good care does not have to be based on principles. The determination of good care depends on contextual factors, and has a different meaning for the stakeholders who define it. Divergent views on quality of care are not regarded as a problem. Rather, communication is required to come to a joint perspective: ethics support is a means to facilitate that kind of communication.

'There is no definition of what good care is. Questions and answers should converge and a common view should develop in interaction.' (Participant FG)

Some stress that ethics support should and will add to the quality of the relationship between caregiver and care-receiver. These respondents refer to the continuous, contextual and situational process which is characteristic for questions about what is good.

"The more fundamental, intense and long term care is, the more you desire quality of care in that relationship. Consequently, more is required from a professional: to asses the situation time and time again and ask oneself the question: what's, for this human being, in this situation, today good care?" (Director of Christian association for health care authorities)

It is expected that ethics support can help practitioners to develop ethical competences like a good attitude to patients:

"That's also ethics: 'I just want to do my job.' But what's that 'just? Do you come and do your business and than exactly at five a clock you close and put the answering machine on? Or do you work with inspiration? And do you engage with the patient: 'no matter what happens, this patient shouldn't be waiting longer than necessary.' I am kind and work 5 minutes longer. It is about that kind of ethics. Why is it so important to put ethics on all these agendas? because we expect that when you address ethical competences and train people in these, attitudes and treatment towards clients will be changed" (Medical ethicist, hospital)

Good care and (improving) quality of care are used as synonyms by respondents. Improving quality of care for example means that the care actions (process), the organization and the care delivered (output) are qualitative high. Some stress that ethics support should be a part of internal quality processes:

‘We trained 25 people to develop ethical qualities within the organisation. They facilitate the dissemination of this knowledge and try to set up dialogues about ethical dimension of care. This is a part of internal quality improvement.’ (Director knowledge centre mental health care institution)

Figure 2 also shows the interrelation between the goals of ethics support in health care institutions. It indicates that health care institutions see ‘good care’ as the ultimate goal of ethics support. Basically, participants of our study indicate that all (main- and sub) goals with ethics support contribute to the overall goal: ‘good care.’

DISCUSSION

Our findings illustrate that respondents see good care as the overall goal of ethics support (see figure 2) and this is confirmed by previous literature. Authors use different words, for example: improving patient care (Slowther, 2007), to improve the quality of care (Abma et al., 2009), delivering good care (Vanlaere et al., 2010) and facilitating good life (Bolmsjö et. al, 2006ab). Some authors argue that good care or good life should be the overall goal of care and see ethics support as a concrete way to realize this overall goal of care (Bolmsjö et. al, 2006b). Others say good care is a goal much too vague and in need of operationalization (Slowther, 2007). This raises the question to what extent they see good care as a distinguishing parameter of ethics support.

For managerial reasons it might indeed be helpful to operationalize the general goal of good care into smart targets. Such targets focus attention and enable managers to evaluate the effectiveness of ethics support. Yet, such concretizations should fit with the goals of employees, and general goals should not be neglected as they form motivators for ethics support in practice. Our findings indicate that participants in practice stress the link between the higher and ultimate goal of good care, and other goals and sub-goals which are considered as intermediate goals to realize the higher goal of good care. Thus, for example, supporting employees may add to their professionalism, and this may lead to better care. Likewise, for instance, deliberation may improve the quality of care. Such common sense relations are intuitive and hypothetical, but still extremely important as motivators for ethics support. One might say that good care is the driving motivator behind ethics support in practice, and we argue that this ultimate goal – the answer to the question why we are doing all this – is extremely important to encourage people to participate into the whole project of ethics support. People need a higher ideal which resonates with their own and organization goals to be able to join into the idea of ethics support.

Our findings indicate that in healthcare practice attention for ethical issues, awareness of ethical issues, fostering ethical reflection and supporting employees are considered important sub-goals of ethics support. These sub-goals are part of the main goals *encouraging an ethical climate* and *developing professionalism*. An ethical climate has been defined as ‘the organizational practices and conditions that promote discussion and resolution of decisions with ethical content’ (Hamric, 2007). It has been demonstrated that supporting employees helps to create a better ethical climate as it lowers moral distress (Hamric, 2007). Previous literature also confirms the importance of developing professionalism by

ethics support. For example, the sub-goal *reflection* is described by Bolmsjo et al. (2006a), Svantesson et al. (2008), Abma et al. (2009) and Vanlaere et al. (2010). Our findings suggest that particularly these goals (ethical climate, reflection) might play an important role in the practical use, implementation and evaluation of ethics support. We assume, however, that the importance endowed to these (sub-)goals is at least in part influenced by the context of our study. In The Netherlands, where this study was completed, reflection and dialogue are considered highly important. This might be an aspect of the organizational culture of healthcare institutions, and our societal culture more in general, which can be characterized as being egalitarian (Hofstede, 2001). Our egalitarian culture fits with the value endowed to democratic dialogue and deliberation, and the preference for moral case deliberation as the preferred form of ethics support. Our culture also explains why the goal of giving advice was not met with enthusiasm. Advice implies more hierarchy, and acceptance of expert knowledge. This implies that our findings cannot just be generalized to other contexts with a less egalitarian culture.

The model with four clusters of goals of ethics support indicates that in order to realize the higher goal of good care, healthcare institutions have to work on different domains ranging from developing an ethical climate and stimulating professionalism to fostering a responsible organization. We would argue that in order to make the implementation of ethics support feasible it is wise to choose one of the clusters of goals to start with. Ideally the choice for such a cluster of goals is the product of discussions between members of ethics staff, managers and practitioners within the organization, as this will foster the commitment for ethics support. The goal of ethics support should also fit with the culture of the organization. This implies that ethicists should beware of the organizational context they work in, and not just imply or impose their goal on the organization. Caluwé & Vermaak (2003) developed a typology of organizations which might be helpful to match goals of ethics support with the organization context. For example, blue print organizations are characterized by (rational) planning and control. Such types of organization might want to choose to work on the goal of being an accountable and transparent organization. Green print organizations, on the other hand, value learning. Green refers to growth (as in nature) and 'green light,' as the objective is to get peoples' ideas to work. Green organization cultures might prefer to work on professionalism as a goal of ethics support. White print thinking assumes everything is changing autonomously. White reflects all colours and it denotes openness as it allows room for self-organization and evolution. The goal of fostering an ethical climate fits well with white print organization cultures. When working in a white print organization, advocates of ethics support do not necessarily have to define the goals of ethics support beforehand because the characteristic of this kind of organization is that it is not possible to plan everything beforehand.

A limitation of this study is that we could not include the views of caregivers and care receivers on the goals of ethics support in healthcare institutions. However, our respondents - board members and ethics support staff - play an important role in the practical use, implementation and evaluation of ethics support. Furthermore, there might be a positive bias in the sense that people who participated in our study might be more interested in ethics than non-responders who could have other or no goals with ethics support.

Conclusion

This article illustrated which goals key-persons in Dutch healthcare institutions attach to ethics support. We recommend that advocates of ethics support take into account the perceptions in healthcare organisations and distinguish main- and sub-goals, in order to promote the practical use, implementation and evaluation of ethics support in health care institutions. Our model can be used as a tool to foster dialogues about goals between various participants in healthcare institutions. The ultimate goal of good care should be valued as the driving motivator for ethics support in practice. The intermediate goals of ethics support (ethical climate, accountable organization, professionalism) should be connected to the characteristics of the organization culture as a whole. Taking into account the fit between the underlying values of ethics support and organizational culture will foster the acceptance of ethics support within organizations and add to the effectiveness of ethics support. This should not be organized by ethics support staff individually; the choice for intermediate goals fitted to the organization is ideally the outcome of a dialogue between the top of the healthcare institutions, advocates of ethics support and practitioners, as this fosters commitment for ethics support. We recommend further empirical research into the goals of ethics support. Especially, the goals of ethics support which are relevant for caregivers and care receivers, should be subject of deeper investigation. Finally, we recommend further research into the extent in which the goals for ethics support are congruent with the organizational culture and to what extent this congruency influences the success of ethics support. Although goals of ethics support tend to be broad and general, they nevertheless have a strong motivating power, and awareness of a variety of goals related to the cultural context can help integrating ethics support within healthcare institutions.

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REFERENCES

- Abma, T.A., Molewijk, B., Widdershoven, G.A.M. (2009). Good Care in Ongoing Dialogue. Improving the Quality of Care Through Moral Deliberation and Responsive Evaluation. *Health Care Anal* 17, 217–235.
- ASBH Task Force on Standards for Bioethics Consultation (1998). Core Competencies for Health Ethics Consultation. The Report of the American Society for Bioethics and Humanities. ASBH.
- Aulisio, M.P. Arnold, R.M., Youngner, S.J., (2000). Health Care Ethics Consultation: Nature, Goals, and Competencies. In: *Ann Intern Medicine*; 133, 59-69.
- Bolmsjö, I Å., Sandman, L., Andersson, E. (2006a). Everyday Ethics in the care of elderly people. *Nursing Ethics* 13 (3), 249-263.
- Bolmsjö, I Å., Edberg, AK., Sandman, L. (2006b) Everyday Ethical problems in dementia care: a teleological model. *Nursing Ethics* 13 (4), 340-359.
- Caluwé, L. de & Vermaak, H. (2003). Learning to change. A guide for organization change managers. Thousand Oaks: Sage Publications.
- Dauwerse, L., Abma, T., Molewijk, B., Widdershoven, G. (2011). Need for ethics support in healthcare institutions: views of Dutch board members and ethics support staff. *J. Med. Ethics*, doi 10.1136/jme.2010.040626.
- Fox, E., Myers, S., Pearlman, R. (2007). Ethics Consultation in United States Hospitals: A National Survey. *The American Journal of Bioethics* 7(2), 13-25.
- Greene, J. C. (2007). *Mixed Methods in Social Inquiry*. San Francisco: Wiley & Sons.
- Hamric, A.B., Blackhall, L.J. (2007). Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Crit Care Med* 35 (2), 422 – 429.
- Hofstede, G. (2001) *Cultures Consequences Comparing Values, Behaviors, Institutions and Organizations across nations*. Thousand Oaks: Sage publications.
- Mertens, D.M. (2010). *Research and evaluation in Education and Psychology. Integrating Diversity with quantitative, qualitative and mixed methods*. Washington D.C: Sage publications.
- Molewijk, B., Verkerk, M., Milius, H., Widderhoven, G. (2008). Implementing moral case deliberation in a psychiatric hospital: process and outcome. *Med Health Care and Phil* 11, 43-56.
- Racine, E., Hayes, K. (2005). The need for a clinical ethics service and its goals in a community healthcare service centre: a survey. *J. Med. Ethics* 32, 564-566
- Reiter-Theil, S. (2001). The Freiburg approach to ethics consultation: process, outcome and competences. *J. Med. Ethics* 27, 21-23.
- Slowther, A. (2007). Ethics Consultation and Ethics Committees. Ch 72 in: *Principles of Health Care Ethics*. England: John Wiley & Sons,. Pp 527 - 532.
- Slowther A, Bunch C, Woolnough B, Hope T. (2001). Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. *J. Med Ethics* 27, 2-8
- Svantesson M, Löfmark R, Thorsén H., Kallenberg, K., Ahlström G. (2008) Learning a way through ethical problems: Swedish nurses' and doctors' experiences from one model of ethics rounds. *J Med Ethics* 34, 399-406.
- Vanlaere, L., Coucke, T., Gastmans, G. (2010). Experiential learning of empathy in a care-ethics lab. *Nursing Ethics* 17(3), 325-336.

Chapter 6



Morality in the Mundane: specific needs for ethics support in elderly care

ABSTRACT

Ethics support is called for to improve the quality of care in elderly institutions. Various forms of ethics support are presented, but the needs for ethics support remain unknown. Using a mixed-methods design, this article systematically investigates the specific needs for ethics support in elderly care. The findings of two surveys, two focus groups and 17 interviews demonstrate that the availability of ethics support is limited. There is a need for ethics support, albeit not unconditionally. Advice-based forms of ethics support are less appropriate as they are removed from practice. Ethics support should be tailored to the often mundane and easily overlooked moral issues that arise in long-term care. Attention should also be given to the learning styles of nurses who favour experiential learning. Raising awareness and developing a climate of openness and dialogue are the most suitable ways to deal with the mundane moral issues in elderly care.

Keywords

clinical ethics, clinical ethics committees, elderly care, ethics consultation, everyday ethics

INTRODUCTION

There is increasing international awareness that attention should be given to the further development of elderly care to maintain or improve the quality of care.^{1,4} The volume of elderly care is increasing as a consequence of the growing number of clients resulting from the increasing numbers of older citizens in the population. Cost cuts, the sector's negative image, care standardization, an ever increasing workload, and understaffing all impose a heavy burden on elderly care.⁵⁻⁸

Nurses and care assistants in elderly care are confronted with various ethical issues.^{7, 9-12} Ideally, a nursing home should provide a living context where residents can live in accordance with their own standards. However, life in an institution is seldom a continuation of life as it was at home. Living in an institution inevitably means that personal preferences and autonomy are curtailed by the necessary routines, the presence of fellow residents, family members, dependency on professional caregivers and limited resources.^{13,14} Nursing homes still resemble the 'total institution' depicted by Goffman in the 1960s,¹⁵ in spite of recent developments such as person-centred care, hospitality care, and small-scale living. Nurses must deal with conflicting interests,¹⁶ difficult behaviour,¹⁷ limited resources, and social problems stemming from a community of residents who did not choose to live together.^{13,18}

A seemingly easy situation, such as the routine of washing older adults involves a set of complex values such as dignity, autonomy, bodily integrity and wellbeing.⁹ However, the complexity of such a situation is easily overlooked as working routines and habits lend structure to daily care.^{9,19} Moreover, given the relatively low formal education and training of most nurses, reflection in long-term care and enduring client-professional relations are challenging.^{13,20}

Several forms of ethics support have been introduced to help nurses deal with moral issues.^{9,11,12,21,22} The most common form of support is the clinical ethics committee.²³ Some authors have observed that a traditional ethics committee tends to be far removed from practice²⁴⁻²⁶ and some studies promote alternative forms of ethics support for long-term care, i.e. moral case deliberation,²⁷ ethics rounds²⁸ and a care-ethics lab.⁹ To date, no systematic studies have investigated the extent to which the range of ethics support currently on offer actually meets the needs of ethics support in elderly care.

This article systematically assesses the specific needs for ethics support in elderly care. The research question is: 'What are the specific needs for ethics support in elderly care?' The data are based on a mixed methods study conducted among elderly care organizations in the Netherlands. This study focused on the ethics support currently available, on evaluating these forms of ethics support, and on the needs for ethics support in elderly care. The argument is that the specific moral issues that arise in elderly care and the learning styles of nurses have implications for the kind of ethics support that best fits with institutionalized elderly care. Here, the term nurses also includes care assistants.

METHOD

Design

An integrated mixed methods design was used i.e. quantitative and qualitative methods were intentionally mingled during the research process.²⁹ Two surveys were prepared using qualitative instruments. Survey data were used as input and validated in two focus groups and in face-to-face interviews (N=17). Table 1 presents a detailed description of the procedures followed. Data were derived from a larger study that included all healthcare sectors. This article first describes the methods used in the larger study and then focuses on our findings regarding elderly care, which is, in fact, the largest care sector in the Netherlands.

Table 1: Data collection procedures

Activity	Survey questionnaire 1	Survey questionnaire 2	2 Focus groups (n = 22)	17 Interviews
Preparation	Literature research 7 expert conversations Pilot: 9 people	Literature research 12 expert conversations Pilot: 12 people	Contact to inform PowerPoint to present results Preparation of hand outs	Contact to inform Topic list
Target group	Board members Addresses (2137) from Dutch government	Ethics support staff Contact information (515) from respondents Q1	Respondents questionnaires 2 days, each day 11 people	Participants research & network. Diversity of sectors
Procedures	2 reminders, phone follow-up	2 reminders, phone follow-up	Dialogue in 2 separate groups Member check	Recording and transcription Member check

Data collection, analyses and quality procedures

The need for ethics support was investigated using two survey questionnaires, prepared by reading the literature and talking to experts from different fields. Both questionnaires focused on the needs for ethics support, the goals of ethics support, and the different forms of ethics support.

Questionnaire 1 was directed at the board members of healthcare institutions. It was developed by reading the literature, talking to experts (N = 7) from different sectors and testing the questionnaire with board members and experts (N = 9) from various sectors. The participants found our questionnaire too long, and board members were not the right people to answer some of the questions. We searched for ways to get as much information as possible in a short questionnaire. The main topics we wanted to ask the board members about were included in the short questionnaire based on Slowther.²³ We added open-ended questions on the goals of ethics support, the desirability of ethics support, and on existing forms of ethics support. An additional advantage of using Slowther's questionnaire was that we were able to place the results in an international context.

This (postal) questionnaire 1 was sent to all intramural healthcare institutions (N = 2137) registered with the Netherlands Ministry of Health, Welfare and Sports (Table 2), and included elderly care establishments, hospitals, mental healthcare and institutions for the mentally disabled. The data collection (April-July 2008) included two reminders and a telephone follow-up. The 2137 individual healthcare institutions turned out to be members of 864 legal bodies, i.e. umbrella organizations with a legal status. Hence, there are two response rates for this first questionnaire, namely 30% (638 / 2137) at the individual institution level, and 56% (485 / 864) at the legal body level.

Questionnaire 2 was distributed to ethics support staff, who are, generally speaking, professionals involved in organizing, implementing and executing ethics support in their institutions, such as the chairs of ethical committees, or spiritual caregivers. The questionnaire was also developed by reading the literature and by holding discussions with experts (N = 12) from different sectors, for example, people with methodological experience in (digital) surveys and people with substantial knowledge of ethics support. This questionnaire was first tested among 12 experts from different fields, who completed the questionnaire and gave feedback by email. Questionnaire 2 included the questions that the board members were unable to answer in the pilot e.g. on content, participants, integration and evaluation of ethics support.

This (digital) questionnaire 2 was sent to all the ethics support staff members (N = 515) designated by the respondents in questionnaire 1. The number of ethics support staff members was less than the number of respondents for questionnaire 1 (N=638) because not all respondents in questionnaire 1 designated a best informant. The data collection (April 2009-July 2009) included 2 reminders and a telephone follow-up. The response rate was 48% (247 / 515).

Elderly care (care homes, nursing homes and sometimes home care) is the largest group (78%) in the research population of the original study (see Table 2), and it is also the group with the highest response rate in the dataset. More than half the respondents (62% for questionnaire 1, and 55% for questionnaire 2) are from elderly care (see Table 2).

Table 2: Research population and response to original study

Sector/ respondents	Questionnaire 1 board members				Questionnaire 2 ethics support staff			
	Population		Response		Population		Response	
	N	%	n	%	N	%	n	%
Elderly care ³	1660	78%	397	62%	308	60%	135	55%
Mentally disabled	186	9%	78	12%	72	14%	30	12%
Hospital	171	8%	99	16%	82	16%	48	19%
Psychiatric institute	120	6%	64	10%	46	9%	19	8%
Other ⁴	-	-	-	-	7	1%	15	6%
Total	2137	100%	638	100%	515	100%	247	100%

³ These are sometimes combined centres with assisted living facilities, including home care.

⁴ For example: sensory disabled, youth care, social service, acquired brain injury, physically disabled.

The data provided by the questionnaires were analyzed separately and transformed for further analysis and comparison (crossover track analysis).²⁹ The closed questions were first analyzed using MS Excel and SPSS 15. Subsequently, the answers to the open-ended questions were labelled and clustered into (sub)themes following an inductive qualitative analysis. Relations were visualized in a mind map and discussed in the research team and validated in the advisory committee and the focus groups.

We organized two focus groups (summer 2009) which were attended by participants who had completed the questionnaires. The groups were a mix of board members/directors, ethics support staff, general staff members and a healthcare professional. There were 22 participants, including 7 participants from elderly care. The elderly care participants were 3 staff members (including 1 who was also head of the ethics committee), 1 head of the ethics committee, 1 spiritual caregiver, 1 director, and 1 nursing home doctor). The meeting itself was structured by the issues emerging from the surveys, and followed an agenda that left ample room for exploration and dialogue. Each two-hour session was moderated by an experienced senior researcher and the first author. Group dynamics were taken into account. The initial analysis of the data from both questionnaires was discussed. Furthermore, they also completed a handout about the preliminary findings. The conversations were analyzed and a summary sent to the participants for validation (member check). Any additional email and telephone responses were incorporated in the further analysis.

Semi-structured interviews (N=17) were conducted to establish corroboration and to gain a deeper understanding of the findings. The interviewees included three people from elderly care, 1 staff member and the head of an ethics committee, 1 staff member from an elderly care umbrella organization, and 1 staff member from a centre of expertise for long-term care. The interviews were conducted by the first author and lasted about 1.5 hours. Themes again included the need for developing goals for ethics support, and the forms of ethics support. The interviews were recorded, analyzed, returned for validation (member check), and used to establish corroboration and gain a deeper understanding. The analysis of the focus group and interview transcripts followed a thematic content analysis. Transcripts were read for recurring themes, which were labelled and clustered until a robust framework was developed. The analysis was completed by the first author together with a team of senior researchers. The combination of methods (triangulation procedure) added breadth to the study, and the qualitative data helped provide explanations for the numeric data from the surveys.

Ethical considerations

Informed consent was obtained by an explanatory introduction letter to respondents of questionnaire 1 and 2. Prior to the meeting, participants of the focus groups and interviews received information by telephone and / or email about the focus group or interview. At the start of the meeting there was a short presentation of the preliminary findings and afterwards they received a member check for agreement. Respondents participated voluntarily. Anonymity was guaranteed by not using names in the analysis and reports.

RESULTS

Ethics support in elderly care

Currently, ethics support, as in the existence of ethics committees (56% are without), moral case deliberation (64% are without), and ethics consultants (92% are without) is severely limited in elderly care in the Netherlands. When a moral question arises in elderly care, other forms such as pastoral care (78% have this), group meetings in the form of multidisciplinary meetings (65% have them), or policy-like guidelines (54% have them) are used (see Table 3). The findings in Table 3 also show that ethics support is not automatically considered to be important in elderly care institutions. For example, only 23% of the ethics committees are deemed to be important within the institution (see Table 3). Collaborative meetings, such as multidisciplinary team meetings, are the most highly esteemed (26%).

Table 3: Assessment of ethics support in elderly care (Questionnaire 2, n=135)

	Available		Not available		(Most) important		Not (most) important	
	Number	%	Number	%	Number	%	Number	%
n = 135								
Individual(s) ⁵	105	78%	30	22%	20	15%	115	85%
Group meeting(s) ⁶	88	65%	47	35%	35	26%	100	74%
Policy	73	54%	62	46%	10	7%	125	93%
Ethics committee	60	44%	75	56%	31	23%	104	77%
Other committee(s) ⁷	59	44%	76	56%	7	5%	128	95%
Ad hoc	58	43%	77	57%	9	7%	126	93%
Education	53	39%	82	61%	18	13%	117	87%
Moral Deliberation	48	36%	87	64%	21	16%	114	84%
Peer assessment	27	20%	108	80%	7	5%	128	95%
Ethics consultant	11	8%	124	92%	3	2%	132	98%

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Need for ethics support

The findings indicate that there is a very real need for ethics support. 67% of elderly care institutions experience a considerable need for ethics support. However, this need is not unconditional as 34% of respondents (questionnaire 1) disagree with the statement that ethics support is desirable (see Table 4).

⁵ This individual is not an ethics consultant

⁶ This group is not moral case deliberation

⁷ This committee is not an ethics committee

Table 4: Need for ethics support elderly care (questionnaire 1, n = 397)

	Number	Percentage
Strongly agree there is a need	73	19%
Agree there is a need	186	48%
Disagree there is a need	111	29%
Strongly disagree there is a need	19	5%
Total	389	100%

Conditional need

The answers to the open-ended questions in the first questionnaire (Q1) illustrate that some elderly care institutions see no need for ethics support because they are satisfied with their existing forms of ethics support:

‘Regular, informal deliberation is enough.’ (Q1, director, nursing home)

Respondents also indicate that the need for ethics support may not be evident or even espoused. They explain that the ethical dimension of care is implicit and therefore the need is hidden:

‘I’m convinced there is a need, but what makes it complicated is that this need is hidden from view.’ (interview staff member centre of expertise for long-term care)

Some argue that moral issues in elderly care do not arise very often and if they do, they are not particularly complicated. For example, they compare their situation with hospitals where, given the complex and structural nature of medical ethical issues in that context, the need for ethics support would be more obvious. The following is from the chairman of a board who probably has a traditional view of ethics and is not aware of the mundane nature of many ethical issues:

‘Ethical issues in our care home generally tend to be incidental and less complex than those in, say, a hospital.’ (Q1, chairman of the board, health care centre with assisted living facilities)

Elderly care institutions may not give priority to ethics support for organizational reasons such as the size of the healthcare institution: *‘It is important, but our care home is too small’* (Q1, care manager, health care centre with assisted living facilities); and the spiritual background: *‘The Bible is the precept behind all our care and services.’* (Q1, director, health care centre with assisted living facilities).

Some respondents have also noticed a discrepancy between what elderly care institutions want and what they actually have in place. They want to use ethics support to help

them deliver good care, yet they do not embark on ethics support because there are so many other priorities and because implementing ethics support would change the organization.

'All those organizations really have a lot on their plate. So, because there are so many other priorities, if they have to make a choice, they won't, out of the blue, just implement some kind of ethics support. It really is something that organizations do want to get up and running, but it's quite intensive because you actually shake the very core of your organization.' (interview staff member centre of expertise for long-term care)

Specific needs

The data of this study as a whole indicate that elderly care has specific needs regarding ethics support. Most board members concur that ethics support is desirable (see Table 4) and the answers to the open ended questions explain the specific needs for ethics support in elderly care. Firstly, the moral issues in elderly care require ethics support. Secondly, given the characteristic moral issues and skills required of nurses working in elderly care, it is a very specific kind of support that is needed.

Moral issues in elderly care

The answers to the open-ended questions illustrate that the type of moral questions influence the specific need for ethics support in elderly care:

'Employees are confronted every day with questions from an ever increasing group of elderly, vulnerable clients.' (Q1, regional manager, healthcare centre).

The findings indicate there is some discrepancy as to the perceived number of moral issues in elderly care. A minority of respondents indicate that moral issues are uncommon in elderly care. Conversely, most respondents emphasize that there are many complex questions that require more structural and systematic attention. They point to care ethical questions, organizational constraints, and nurses' attitudes.

Several board members and ethics staff members emphasize that ethics is much broader than dilemmas about life and death.

'Ethics support is absolutely essential when caring for frail and vulnerable people; it influences what you do, and it's a basis to help you make decisions.'

(Q1, spiritual caregiver, nursing home)

'Ethics is an everyday issue, when are you doing the right thing, and for whom is it the best thing to do? Ethics is more than dilemmas about life and death.'

(Q1, head of the day-care unit, health care centre with assisted living facilities)

The quantitative findings of questionnaire 2 (see Table 5) confirm that there are not many medical ethical issues in elderly care (40% indicate that these kinds of questions do not arise frequently).

Table 5: Type of questions (questionnaire 2: ‘How often do the following ethical themes arise in your healthcare institution?’)

Question / Number	A lot / enough		Some / several		None		Total		Explanation
	%	n	%	n	%	n	%	N	
Medical ethical	26%	35	34%	46	40%	54	100%	135	Medical ethical themes in relation to difficult decisions (euthanasia, abortion, drip feeding, coercive admission, reproduction)
Care ethical	43%	58	31%	42	26%	35	100%	135	Care ethical themes (am I allowed to wash a patient who doesn't want me to? Am I allowed to inform family about the care policy when the patients don't want this?)
Organizational	58%	77	30%	39	12%	14	100%	132	Organizational themes (for example development of organizational vision, savings, waiting lists, scarcity)
Attitude	73%	98	16%	22	11%	14	100%	134	Attitudes (for example: how to treat someone?)

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However, moral questions about one’s attitude as to how to treat someone do emerge frequently (73%). These questions often generate a feeling of powerlessness: ‘*When you really have the idea that you can’t do anything to make life more pleasant for the residents.*’ (interview with staff member of an umbrella organization for elderly care). As a nurse it is obviously very difficult when you feel you cannot influence the situation: ‘*When you really have the feeling that you can’t do anything to make someone’s life easier and more pleasant.*’ (interview staff member centre of expertise for long-term care).

Respondents point out that nurses in elderly care have less professional training in ethics than, for example, registered nurses in hospitals. Those respondents who understand ethics to encompass more than medical ethical issues such as end-of-life decisions are not satisfied with how nurses currently deal with the moral dimension in healthcare:

'They are confronted with ethical questions, but they are not fully equipped to recognize or deal with them.' (Q1, board member, health care centre with assisted living facilities)

Nurses tend to associate ethics with medical ethical issues such as respect for autonomy, tube feeding, resuscitation or euthanasia, while most ethical questions in elderly care actually different. For example:

'An old lady with dementia and diabetes who wants to eat cake every day. When you believe she's autonomous, then you should let her have cake every day, but then that doesn't feel like being a good caregiver.' (interview staff member centre of expertise for long term care).

Several respondents state that nurses do not have sufficient skills to identify and deal with ethical issues. They indicate that nurses in elderly care do feel when there is an ethical question, but they are unable to say what it is:

'They often experience a feeling of powerlessness without recognizing the ethical basis of the situation.' (focus group participant, staff member elderly care).

Nurses feel uncomfortable, but simply return to their routines in order to deal with the unpleasant feeling they experience since they see no alternatives. One interviewee comments that employees wrongly assume that giving attention takes time:

'When serving food there was one caregiver who waited until the patient answered "thank you" after she had said "enjoy your meal." The others just got on with handing out food without waiting for an answer: ...enjoy your meal, enjoy your meal, enjoy your meal...' (interview staff member centre of expertise for long-term care).

Specific support

Given the type of moral issues to be found in elderly care, and the skills of the nurses involved, respondents postulate that specific ethics support is needed, which, they believe, is up to the organization to facilitate. In elderly care, particularly those people with an exemplary role can be very supportive for nurses, so that they learn how to deal with ethical questions:

'It's all about how people learn. Most caregivers in elderly care don't learn from theory. They tend to learn from good examples, by copying the behaviour of role models. If there's a team with colleagues they respect and admire then they might think something like "I'd also like to do it the way they do". In these cases many beautiful things happen. They're often new people or students.' (interview staff member centre of expertise for long-term care)

Respondents suggest that elderly care might possibly require forms of ethics support that differ from what is found in other healthcare settings, particularly because nurses in elderly care lack confidence and do not feel appreciated for the effort and energy they put into their work. The broader political image in society at large of what elderly care entails actually exacerbates the situation and results in nurses being ashamed of working in elderly care. Ethics support should help get the work of these nurses recognized, rather than introducing yet another innovation or course that may again be perceived as criticism of their effort:

'Elderly care is not really appreciated. Nurses should get more support, more recognition. It's only when they become aware that they really do make a difference that they'll start to appreciate themselves and again be proud of their profession. For example, if asked about their job at a party, they hardly dare say they are nurses. They are usually associated with urine and faeces instead of with wellbeing, whereas for me it is wellbeing that really counts.' (interview staff member centre of expertise for long-term care)

Respondents argue that implementing ethics support as 'yet another' course only serves to foster the feeling that nurses 'do not do enough', while in fact they actually give a lot of themselves. There is a tension here for elderly institutions because, on the one hand, they should not introduce 'yet another innovation,' but on the other hand they are assumed to be responsible for ethics support, as the following quote illustrates:

'Employees who have to deal with difficult questions are entitled to get support for this in their work.' (Q1, spiritual caregiver & member of ethics committee, care home)

Respondents prefer not to opt for a specific form of ethics support and advocate a combination of different forms: most often cited are - group deliberation (informal: 26%; in a committee: 23%; moral case deliberation: 16%). Apparently there are advantages to group deliberations, as the following respondent illustrates:

'Ethical dilemmas are sometimes discussed during team or work meetings. Perhaps this isn't really official support, but in practice it is meaningful and useful to make an ethical decision in a short space of time.' (Q2, nursing home physician, nursing home)

Furthermore, many elderly care institutions reject isolated forms of ethics support. Respondents prefer integrated ethics support which blends in with daily activities i.e. it is not something new, and low threshold. Ethics should become a shared responsibility. Role models and leadership are essential:

'Don't formalize it as a "service." That only involves extra money and leads to problems; easy accessibility would disappear. Rather define it as an integral

responsibility.’ (Q1, chairman of the board, health care centre with assisted living facilities)

‘Employees and management should feel and behave responsibly because otherwise they might think that “the ethics committee is responsible for this.”’
(Q1, site director, care home)

‘Directors say it’s important that the work floor is ethical, but they don’t get involved themselves. And their involvement really is necessary if the goals of ethics support are to be achieved.’ (FG, staff employee elderly care)

Therefore, elderly care institutions have a need for organized and integrated low threshold, familiar ethics support.

DISCUSSION

Our findings illustrate that ethics support in elderly care institutions in the Netherlands is limited. There is a need for this kind of support, albeit not unconditionally. The data indicate that advice-based forms of ethics support transcend and do not match up with the nature of moral problems found in long-term care. The belief is that advice-based forms of ethics support are far removed from actual practice and that they are not in tune with the real issues in the workplace. Several authors describe the advantages and disadvantages of ethics committees,²⁴⁻²⁶ and they confirm that the extent to which a committee is appropriate for creating a communication platform for mundane issues is ambiguous.

Many moral issues in elderly care arise daily, and often involve seemingly ‘trivial’ issues. The literature refers to this as ‘everyday ethics.’^{11,12,14,17} which includes everyday practice, the routines and encounters with clients and relatives. Everyday ethics looks beyond the extra-ordinary dilemmas, such as death and dying – the traditional focus of bio-ethics³⁰ - and broadens the scope to the context in which ethical dilemmas arise.³¹ One problem observed in our study is that everyday ethical questions may be overlooked or found to be, as Caplan puts it, ‘mundane’ or ‘banal’.¹⁴ Our respondents argue that ethics support should therefore first and foremost help nurses recognize and identify these problems as being moral problems. This corresponds with the literature that says that explicit attention should be given to the moral dimension of daily practice, as ‘the challenge of recognizing everyday ethical issues lies in their ordinariness.’³² Blind spots may easily arise in institutional settings that are regulated by a rigid regime and working routine.

Another emergent characteristic of everyday ethics is that many moral problems are continuous in nature. End-of-life decisions are irreversible: once a decision has been taken, nurses have to deal with the consequences. The majority of moral issues in elderly care are not irreversible decisions but problems that last much longer. This also implies that everyday ethical questions often create more space for experimentation and for trying out different options. Yet this space for creative interaction can only be used if there is ongoing evaluation of delivered care, underlying values and an analysis of the context.¹¹ As Caplan rightly states: ‘everyday questions are no less deserving of careful thought and deliberation.’¹⁴ This

implies that ethics support should create space for reflection in order to encourage nurses to experiment in their dealings with elderly clients.

Our respondents indicate that specific needs for ethics support are also related to the nurses' education level. Daily care (e.g. personal care, leadership on the ward, assistance at mealtimes) is generally provided by lower educated and cheap nursing staff.¹³ They are task oriented³³ and focus on practical work.² These nurses also prefer to learn in concrete and active ways³⁴ and can, as Kolb puts it, be typified as 'accommodators.'³⁵ In an empirical study in two nursing homes and six care homes in the Netherlands, Snoeren³⁴ found that lower educated nursing staff were less capable of perceiving abstract problems, were reluctant to change, often did not analyze problems thoroughly and therefore found it difficult to evaluate solutions. Negative communication patterns within the team and a tendency for a quick evaluation or for no evaluation at all, and waiting for the manager to solve a problem can also obstruct learning processes.^{34, 36, 37} found that an important strategy for dealing with difficult situations is the use of former experience, by applying solutions that have proven successful in the past. One risk of this strategy, also known as casuistry, is that experience and solutions become private and are not discussed in the team. This means that dialogue and group learning cannot take place. Traditional ethics support does not match well with these learning styles and the need for collective learning.

We should not overlook the problems related to the context in which the nurses work. Our respondents draw attention to feelings of powerlessness as a human response to the chasm between their low educational level and the complex questions they encounter. Instead of being recognized for the difficult work they do, nurses are overloaded with new assignments and innovations which may, in turn, further increase their feeling of powerlessness. There is a need for empowerment rather than for just another form of ethics support.

Limitations of the study

Our findings are somewhat limited because we only included the perspectives of board members and ethics support staff in the elderly care institutions. However, this is the first broad overview of ethics support, and it clearly forms the basis for further research into the needs for ethics support, also with other stakeholders in elderly care.

Furthermore, the empirical data were collected in the Netherlands, so therefore it remains unclear to what extent these findings can also be applied in an international context. However, because the international literature corresponds with many of our results, the findings might be relevant for other countries outside the Netherlands. Moreover, this article can serve as a starting point for a discussion about the need for ethics support in elderly care abroad.

Recommendations

Since many issues in elderly care are mundane and long term, it is important to focus ethics support on reflection and learning instead of on decision making. Reflection here refers to being able to get a handle on complex situations, understanding their complexity and the underlying values and duties.

Ethics support should also be adapted to the learning styles of nurses and focus on reinforcing learning. It is recommended that a developmental perspective be taken and that once formal education has been completed, learning should realistically be continued. Work-based learning is probably a good way to do this. Education is important and should be linked to explicit actions in a specific context. Experiential learning is more appropriate than frontal learning. For example, moral case deliberation (mcd) stimulates reflection and mutual learning. Another example of ethics support grounded in concrete experience is the recently developed sTimul care ethics lab. This is an educational setting where nurses take the role of a patient in order to experience what it means to be a care-receiver. After preparation and selection the participants join a so called ‘empathy session’ of two days in which they receive care from nursing students. During the session the simulation exercise is stopped twice to invite both groups to reflect on their experiences. After two months there is a follow-up including a return-day for the nurses and ethical reflection in lessons for the students. The personal and embodied simulation of the vulnerability of older care-dependent people leads to an enhanced insight into ethical intuitions and expression of ethical perceptions.⁹ What these approaches also share is that they build on the moral insights of participants as opposed to following the advice of an expert. This is not to say that traditional ethics support models, i.e. ethics committees and consultants, are no longer needed. These forms of ethics support can be complementary: e.g. an ethics committee may help introduce and coordinate mcd or alternatives.

Furthermore, we recommend the development of an ethical climate of reflection-in-action, openness and dialogue. Ethics support should empower nurses and encourage them to be creative. A cultural change might even be more important than simply another form of ethics support. As things stand, it would appear that ethical issues have reached a status quo, whereas what is really needed is a dynamic climate. Such an organizational culture is characterized by openness, it is a context in which something which might appear obvious is questioned. Creative and higher educated nurses may act as role models and foster cultural change in the workplace, if supported by leadership from top and middle management. Middle managers in particular might serve as role models and create the opportunity and space for reflection. We recommend that ethical competences become part of the criteria when recruiting middle managers.

This study was conducted among respondents in the higher echelons of elderly care organizations. We recommend that the need for ethics support also be investigated from the perspectives of practitioners and care receivers in elderly care, namely the residents and their families.

CONCLUSION

Elderly care generates specific needs for ethical support. Everyday ethics in elderly care requires mundane issues to be recognized as moral issues, otherwise they may all too easily be overlooked. The continuous nature of moral problems in long-term care requires methodical evaluation and reflection to be able to optimally use the room for creative experimentation. There should also be room for learning-by-doing and collective reflection to counter the tendency to focus on getting the work done and finding solutions to practical problems

based on former experiences. In addition to an ethics committee or consultant, elderly care institutions might benefit from ethics support that focuses on reflection and learning among nurses. However, this starts with the development of a climate and culture of openness and dialogue, and the recognition of the valuable work done by nurses.

REFERENCES

1. Gurnik M, Hollis-Sawyer L. Empowering assisted living front-line care staffs to better care for Alzheimer's and dementia residents. *Ageing International* 2003; 28(1): 82-97.
2. Solum EM, Slettebø A, Hauge S. Prevention of unethical actions in nursing homes, *Nursing ethics*, 2008; 15(4): 536-48.
3. Franklin LL, Ternstedt BM, Nordenfelt L. Views on dignity of elderly nursing home residents. *Nursing Ethics* 2006; 13(2): 130-146.
4. Pauly B, Varcoe C, Storch J, et al. Registered nurses' perceptions of moral distress and ethical climate. *Nursing Ethics* 2009; 16(5): 561-573.
5. Schaffer MA. Ethical problems in end-of-life decisions for elderly Norwegians. *Nursing Ethics* 2007; 14(2): 242-257.
6. Haggstrom E, Kihlgren A. Experiences of caregivers and relatives in public nursing homes. *Nursing Ethics* 2007; 14(5): 691-701.
7. Rees J, King L, Schmitz, K. Nurses' perceptions of ethical issues in the care of older people. *Nursing Ethics* 2009; 16(4): 436-452.
8. Chen Z, Yua J, Song Y, et al. Aging Beijing: Challenges and strategies of health care for the elderly. *Ageing Research Reviews* 2010; 9s: s2-s5
9. Vanlaere L, Coucke T, Gastmans G. Experiential learning of empathy in a care-ethics lab. *Nursing Ethics* 2010; 17(3): 325-336.
10. Gjerberg E, Førde R, Pedersen R, Böllig G. Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Social science & medicine* 2010; 71(4): 677-684.
11. Bolmsjö I Å, Sandman L, Andersson E. Everyday Ethics in the care of elderly people. *Nursing Ethics* 2006; 13 (3) 249-263.
12. Bolmsjö I Å, Edberg AK, Sandman L. Everyday Ethical problems in dementia care: a teleological model. *Nursing Ethics* 2006; 13 (4): 340-359.
13. Collopy B, Boyle P, Jennings B. New Directions in Nursing Home Ethics. *The Hastings Center Report* 1991; 21(2): 1-15
14. Kane RA, Caplan AL (eds). *Everyday ethics: resolving dilemmas in nursing home life*. New York: Springer, 1990.
15. Goffman, E. *Asylums: Essays on the social situation of mental patients and other inmates*. New York: Doubleday, 1961.
16. Elander G, Drechsler RGN, Persson KW. Ethical dilemmas in long-term care settings; interviews with nurses in Sweden and England. *Int J Nurs Stud* 1993; 30(1): 91-97.
17. Hasselkus BR. Everyday Ethics in Dementia Day Care: Narratives of Crossing the Line. *The Gerontologist* 1997; 37(5): 640-649
18. Rosen T, Pillemer K, Lachs M. Resident-to-resident aggression in Long-term care facilities: an understudied problem. *Aggress Violent Behav* 2008; 13(2): 77-87
19. Jakobsen R, Sørli V. Dignity of older people in a nursing home: narratives of care providers. *Nursing Ethics* 2010; 17(3): 289-300

20. Moyle W, Hsu MC, Lieff S, et al. Recommendations for staff education and training for older people with mental illness in long-term aged care. *International Psychogeriatrics* 2010; 22(7): 1097—1106.
21. Svantesson M, Löfmark R, Thorsén H. et al. Learning a way through ethical problems: Swedish nurses' and doctors' experiences from one model of ethics rounds. *J Med Ethics* 2008; 34: 399-406
22. Dam van der, S., Abma T.A., Molewijk, A.C., Kardol, M.J.M., Schols, J.M.G.A., & Widdershoven, G.A.M. (2011). Organizing Moral Case Deliberation in mixed groups: experiences in two Dutch nursing homes. *Nursing ethics*, accepted July 2010
23. Slowther A. Ethics consultation and ethics committees. In: Ashcroft R, Dawson A, Draper H, et al., eds. *Principles of health care ethics*, John Wiley and Sons, 2007
24. Steinkamp N, Gordijn B. Ethical case deliberation on the ward. A comparison of four methods. *Med Health Care and Philos* 2003;6:235-246
25. Thompson MA, Milburn Thompson J. Ethics committees in nursing homes: a qualitative research study. *HECFORUM*, Vol 2, No. 5, pp. 315-327, 1990
26. Fox MD, McGee G, Caplan A. Paradigms for Clinical Ethics Consultation Practice. *Cambridge Quarterly of Healthcare Ethics* 1998;7:3008-3014.
27. Molewijk AC, Abma T, Stolper M. et al. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *J Med Ethics* 2008; 34:120-124
28. Libow LS, Olson E, Neufeld RR, et al. Ethics rounds at the nursing home: an alternative to an ethics committee. *J Am Geriatr Soc.*1992; 40(1): 95-7.
29. Greene J C, *Mixed Methods in Social Inquiry*. Wiley & Sons. San Francisco. 2007
30. Moody HR. *Ethics in an aging society*. Baltimore: The John Hopkins University Press, 1992
31. Moon M., Taylor HA., McDonald EL, et al. Everyday ethics issues in the outpatient clinical practice of pediatric residents. *Arch Pediatr Adolesc Med.* 2009;163(9):838-843.
32. Powers BA. Ethnographic analysis of everyday ethics in the care of nursing home residents with dementia. *Nursing research* 2001; 50(6): 332-339
33. Tuckett AG. Residents' rights and nurses' ethics in the Australian nursing home. *International nursing review* 2005; 52: 219-224
34. Snoeren MWC & Dekker-VanDoorn CM. Leren=veranderen. Een kwalitatief onderzoek naar de relatie tussen veranderingsprocessen en de leerstrategie van lageropgeleide medewerkers. [Learning=changing. A qualitative research of the relationship between changing processes and the learning strategy of lower educated practitioners.]. *Verpleegkunde* 2007; 22(2): 86-97
35. Kolb DA. *Experiential learning: experience as the source of learning and development*. Englewood Cliffs, New Jersey: Prentice Hall, 1984
36. Dam, van der S, Abma TA, Molewijk et al. Organising moral case deliberation in mixed groups: experiences in two Dutch nursing homes. In press: *Nursing Ethics*.
37. Slettebø A & Haugen Bunch E. Ethics in nursing homes: experience and casuistry. *International journal of nursing practice* 2004; 10: 159-16.

Chapter 7



General Discussion

7. GENERAL DISCUSSION

7.1 Introduction

Over the past decades, the attention on clinical ethics has increased in the Netherlands. New kinds of ethics support like MCD have been introduced. The growing attention on and implementation of different kinds of clinical ethics support gives rise to various questions. What kind of clinical ethics support is available in health care institutions? What kind of clinical ethics support is needed for dealing with current ethical issues in health care? In this thesis we have addressed these questions, focusing on the Dutch context.

The aims of this study were to provide an overview of: 1) the prevalence and characteristics of Clinical Ethics Support (CES) in the Netherlands and 2) the goals and needs of CES from the perspective of top managers and ethics support staff of health care institutions. The central research question is: what is the state of the art of CES in the Netherlands? The sub questions are:

1. How prevalent is CES and what are its characteristics in the Netherlands?
2. What are the needs and goals of CES in Dutch health care institutions?

These questions were addressed with a mixed methods design, integrating questionnaires, interviews and focus groups. We developed two questionnaires. The first questionnaire was addressed to managing directors of all health care institutions. The response rate was 30% (638/2137) at the individual institution level and 56% (485/864) at the legal body level. The second questionnaire was addressed to ethics support staff. The response rate was 48% (247/515). In order to better understand the quantitative data, we gathered qualitative data through interviews with managing directors and ethics support staff ($n = 17$) and two focus groups with ethics support staff and managing directors (each 11 participants). The results were described in articles, published in or submitted to international journals.

In this final chapter we first summarize the main findings. Then we will reflect on the findings from a theoretical perspective. We will use Habermas' notions of system and life world to clarify why various kinds of CES are present in the Netherlands and how they are appreciated by managing directors and ethics support staff in health care institutions. Next, we will reflect on the methods used, and elaborate on their strengths and weaknesses. Finally, we will formulate recommendations for research and practice.

7.2 Main findings

7.2.1 Prevalence and characteristics of CES

The first question to be answered is:

How prevalent is CES and what are its characteristics in the Netherlands?

We answered this research question by assembling data on various kinds of CES, distinguishing between explicit and implicit CES. Explicit CES is described as ethics support which has an organizational structure and a formal position within the institution, providing professional guidance on a structural basis. Explicit CES in Dutch health care includes ethics committees, ethical consultants and Moral Case Deliberation (MCD). Implicit CES refers to informal, spontaneous exchanges of views and experiences on morally difficult situations. Implicit CES entails (team) meetings, spontaneous conversations, and policy or educational settings which are not primarily focused on ethics.

Explicit CES

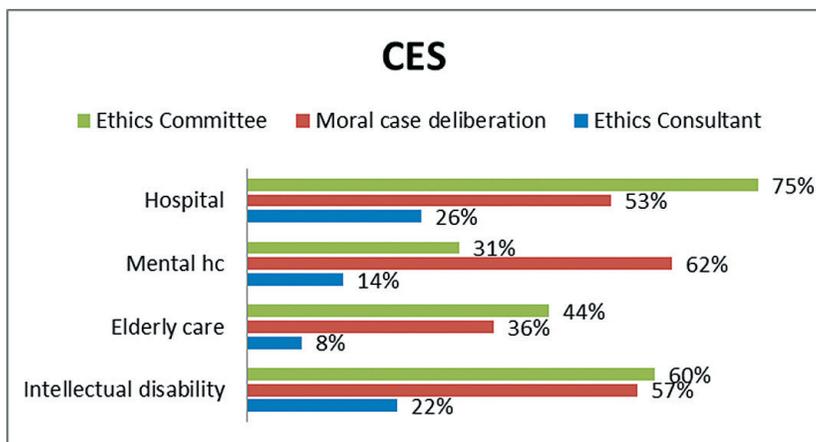
In chapter 2 we provided quantitative data on various kinds of explicit CES in Dutch health care institutions (see figure 1). Compared to 2001, the presence of ethics committees in Dutch hospitals and mental health care institutions seems to have decreased. In a 2001 survey, 89% of Dutch hospitals and 38% of Dutch mental health care institutions reported the presence of an ethics committee.¹ In 2007, 76% of the hospitals, and 31% of the mental health care institutions reported to have an ethics committee. The data are, however, not fully comparable, since the study in 2001 included research ethics committees, which were specifically excluded, since they do not provide clinical ethics support. Moral Case Deliberation was not a research subject in 2001; nowadays MCD is prominent, especially in mental health care, where it is reported as present in the organization by 62% of the respondents. The prevalence of ethics consultation is relatively low, especially in elderly care (8%).

Qualitative research reported in chapter 2 showed that explicit CES stimulates intra-organizational connection, continuity (between experience and knowledge on ethics) and systematic attention for the ethical dimension of care.

In chapter 3, we showed that MCD is offered in 109 (of 247) participating institutions. Institutions with MCD differ from institutions without MCD in size and importance of ideological background.

Chapter 5 indicated that there is a need for explicit kinds of CES, since it makes ethical issues visible, fosters effectiveness of ethical reflection and enables moral learning. Respondents explain that without explicit CES, there is little systematic, but only ad hoc attention for ethical questions.

Chapter 6 illustrated that in elderly care, explicit CES, connected to the learning styles of care workers, is important because systematic attention to the ethical dimension of care is not automatically given. Yet, within elderly care explicit CES is not widely available.

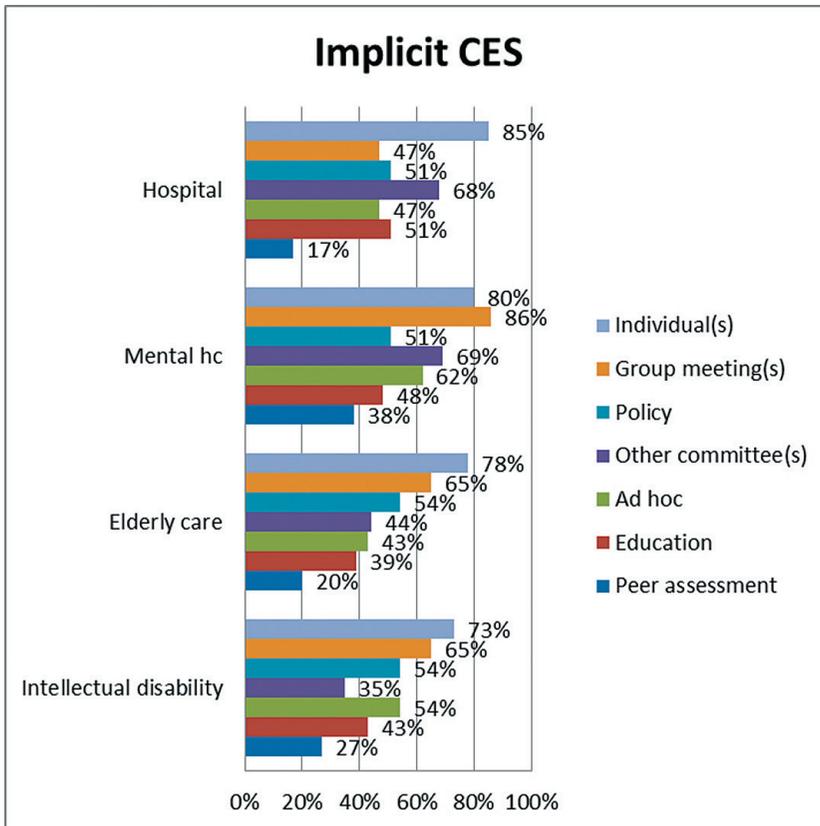
Figure 1: Explicit CES in Dutch health care institutions

Implicit CES

In Dutch health care institutions, various kinds of implicit ethics support can be found (see figure 2 and chapter 2). An implicit individual consultation is an interaction with individual person concerning the ethical dimension of (everyday) care. An example is a spiritual caregiver (e.g. pastoral or humanistic) who supports another individual experiencing a moral question. A group meeting is an existing work meeting in which ethical issues arise. An example is a multidisciplinary team meeting in which a moral question arises. Policy/procedures are existing policy/ procedures with an ethical dimension. An example is a procedure for complaints or an annual report. An 'other' committee is an organizational group which does not aim to deal directly with ethical issues, but addressed them indirect. An example is an identity committee which searches for underlying values which are key for the organization. Education refers to educational activities focusing on the ethical dimension of care. An example is a course in which there is focus on the ethical dimension of care. Implicit kinds of CES are valued and experienced as natural strategies to deal with the (everyday) ethical dimension of care.

Chapter 5 showed that professionals in Dutch health care institutions often have negative associations with ethics. Ethics has the connotation of an activity of a formal body with a high threshold, and ethicists are seen as people who speak a difficult and abstract language. Chapter 6 suggested that implicit kinds of CES might create openings for explicit CES, as implicit forms connect to the learning styles of care workers.

Chapter 6 also showed that, when a moral question arises in elderly care, implicit kinds of CES such as pastoral care (78%), group meetings in the form of multidisciplinary meetings (65%), or policy-like guidelines (54%) are used and deemed to be important within the institution.

Figure 2: Implicit CES in Dutch health care

Relationship between explicit and implicit CES

Our qualitative data (i.e. interviews and focus groups with managing directors and ethics support staff) indicate that explicit and implicit CES reinforce each other and can be combined and developed simultaneously. Explicit and implicit kinds of CES are both required to recognize and deal with moral issues. This implies that explicit and implicit CES should not be regarded as alternatives which exclude each other, but as complementary. Explicit CES is needed since it facilitates systematic and structured attention for the ethical dimension of care in a professional way, with formal tasks and responsibilities (chapters 2 and 5). It makes ethics visible in the organization and contributes to organizational learning cycles by drawing lessons from incidents and individual ethics cases, relevant for the organizational level. Implicit CES is needed since in this context the ethical dimension of care emerges in a natural, narrative way. It is closely related to the actual experience of the ethics of daily care of health care professionals. Together, explicit and implicit CES may help to address complex issues or raise moral sensitivity in current health care.

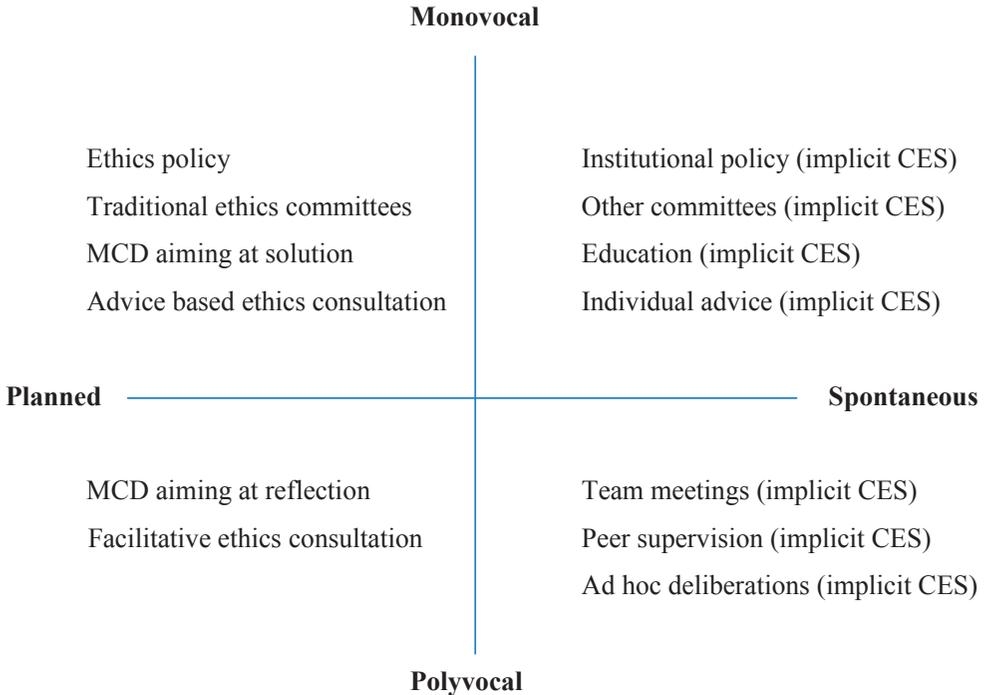
Some kinds of explicit CES, such as MCD, are close to implicit CES, since the ethical dimension of care is presented in a narrative form and the focus is on the actual experience of ethical issues in the daily care of professionals. Peer-supervision can be regarded as a kind of implicit CES that has elements of explicit CES, since it facilitates systematic and structured attention for the ethical dimension of care and contributes to a continuous (ethics) learning process

In order to further interpret the nature of various CES activities we can use the dimensions of organizational change, distinguished by Homan.² He distinguishes between two kinds of activities (planned and unplanned), and two kinds of giving voice (monovocal and polyvocal). As CES activities may contribute to organizational change (in the direction of more attention for ethical issues), they can be interpreted in terms of Homan’s dimensions.

Explicit CES (both traditional and recent forms) are planned in that they start with a small group of people (e.g. the participants of the ethics committee or MCD organizers and facilitators) intending to change a larger group (e.g. in relation to an ethical topic like euthanasia or coercion or in relation to their attitude in relation to moral questions), and designing a strategy on how to bring that about (see figure). No matter how participative one organizes the change trajectory, it is prepared by some people to change other people.²

In implicit CES (both individual and team meetings) the attention to moral issues is not planned. The ethical dimension of care is addressed naturally in a setting without fixed

Figure 3: CES and dimensions of institutional change



structures, or in structures which were planned for another purpose. Deliberations between individuals in which ethical issues emerge spontaneously, such as conversations at the coffee machine, help form and nurture organizational values.²

Explicit CES, like traditional ethics committees, ethics consultants and approaches in MCD focusing on problem solving, and implicit CES, such as institutional policies, committees with an objective which is not explicitly ethical, educational activities, and individuals who provide support with implicit moral questions, tend to entail monovocal activities (see figure 3). Although various participants may be involved, these activities are monovocal, or monological, since they see ethical knowledge as the product of an individual, singular self who is responsible for arriving at an objective judgment through the right use of rational capacities.³ These kinds of CES presuppose that one can ‘solve’ ethical problems and that an ethicist is an expert who ‘thinks through’ ethical difficulties, and gives advice to others. From this perspective, the persons involved in a case are seen as providers of information or as receivers of advice.

Polyvocal

Recent developments in explicit CES, such as the facilitative approach for ethics consultation⁴ and MCD methods aiming at reflection and dialogue,⁵ can be interpreted as polyvocal. In these planned CES activities, a larger chorus of voices is included and ‘slow’ questions, which invite reflection on values (versus ‘fast’ questions, which invite concrete answers and actions) are put on the agenda. Likewise, implicit CES, such as reflective team meetings, peer supervision and ad hoc deliberations on ethical issues can be polyvocal, and show aspects of dialogical consciousness, such as intersubjectivity, understanding and engagement.³ These kinds of CES are reflective practices, striving at mutual moral learning. CES starting from a dialogical stance does not depart from predetermined principles, but aims at determining what is good through a procedure (dialogue), enacted by the actual parties involved.⁶ Moreover, it assumes that universal answers and solutions to ethical dilemmas are not available and therefore considers dialogue not as an instrument or technique to reach better decisions, but as an ongoing, social learning process in which participants develop richer understandings of their practice.⁷

Our study shows that CES is not limited to planned, monovocal activities. Next to traditional ethics committees, various other kinds of CES are important, focusing not on planned, but on spontaneous support, or fostering dialogue in a planned way. This is in line with previous literature, which shows an increase in kinds of CES which are open for everyday problems and take the experiences of stakeholders as starting point.^{8,9} Implicit kinds of CES have an important role in developing new values and perspectives (Homan refers to these as ‘clouds of meaning’). Dialogue based explicit forms of CES (like MCD) might serve as a bridge between explicit and implicit kinds of CES.

7.2.2 Needs and goals of CES

In this section we will answer the second research question:

What are the needs and goals of health care organizations concerning CES?

This research question focused on the changing needs for and goals of CES in the organization.

Needs for CES in health care organizations

Chapters 4 and 6 illustrated that the needs for CES in Dutch health care are varied.

Most respondents (68%) see a need for ethics support (Chapter 4). This need is related to the complexity of contemporary health care, the contribution of ethics support to the core business of the organization and to the added value of paying structural attention to ethical issues. The need for CES is, however, not unconditional, since 32% of respondents disagreed with the statement that CES is desirable. Reasons for a lack of need include: aversion to innovation, negative associations with the notion of ethics support service, and organizational factors, like resources and health care setting.

The data presented in chapter 4 suggest that respondents who experience a need for CES, see ethics as an inherent part of contemporary health care practice and indicate that ethics is not limited to major medical ethical issues like euthanasia and abortion. They stress that CES should not only be used to reflect on and to justify large decisions and policy decisions, but that it should be visible in daily activities and become integrated in the veins of the organization. Chapter 4 also showed that traditional CES is often considered distant, lacking participation of all stakeholder groups and not fitting in organizational learning cycles. In order to correlate to the needs of practitioners, a low threshold for participation is required.

The needs concerning CES seem to be related to developments in health care, described in the introductory chapter of this thesis. Changes in patient population, professional knowledge and organization of care require ethical reflection. Our respondents search for kinds of CES which help them to deal with mundane ethical issues. They, for example, indicate that having an ethics committee does not automatically imply that there is attention for everyday ethical issues and stress the importance of implicit kinds of CES (like ‘coffee chats’) for developing an ethical climate. Having explicit CES does not automatically imply that there is attention for the ethical dimension of care nor does a lack of explicit CES automatically mean that institutions do not have (implicit) attention for the ethical dimension of care (chapter 2).

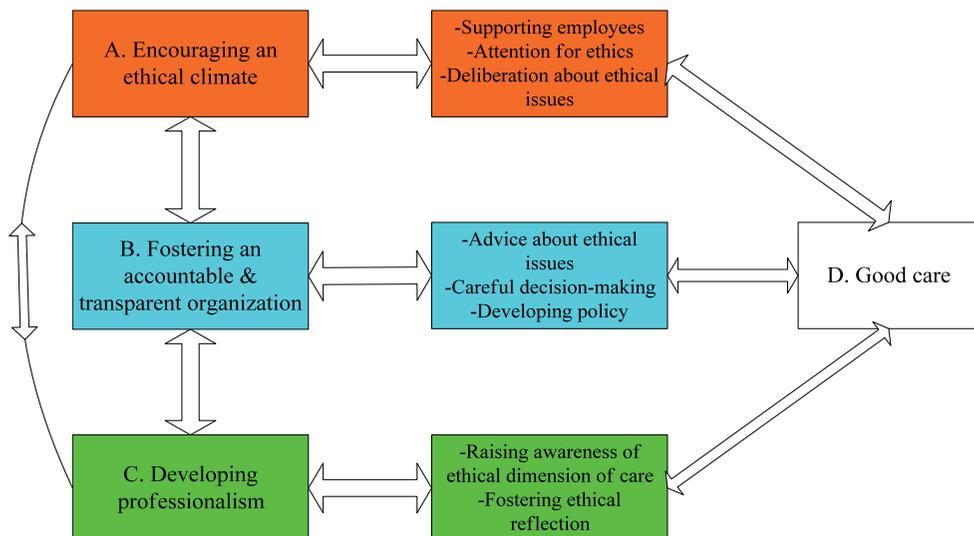
In elderly care (chapter 6), a specific approach to CES is needed, in line with the context or setting. This chapter showed that the context of elderly care is characterized by mundane ethical issues and has a need for creative kinds of CES, connected to the ways of learning of nursing aids and the nature of ethical issues. To fulfill these needs, it is important to connect to the experiential learning styles of care assistants, increase the involvement of all stakeholders, and create conditions for dialogue which are desired in contemporary health care. An increasing group of (elderly care) institutions uses dialogical CES to meet the needs of health care professionals. Dialogical CES is characterized by including many stakeholder groups, paying focusing on everyday ethics and a narrative, and using implicit CES. MCD and the care ethics lab can be seen as dialogical kinds of CES which contribute to the needs in relation to CES in elderly care. As such, dialogical CES might provide a suitable way to develop a climate of openness, which is an important condition for dialogues on values.

In sum, our data suggest that there is no longer a need for CES which functions as a separate service (as traditional ethics committees did). A ‘one size fits all’ solution is not considered to be sufficient for contemporary health care and ethics should be integrated in daily practice, in order to get the desired and required attention. Dialogical CES (like MCD) are seen as an answer to this need, providing a moral inquiry based on experiential knowledge and acknowledging moral expertise from every single participant. Within dialogical CES a wide range of perspectives on ethical issues is addressed and ethical topics are the focus of systematic deliberation, based on equal participation. In dialogical CES, the meaning of ethics for daily practice is a continuous subject of dialogue, contributing to the development of a shared ethics language and low thresholds in dealing with moral questions arising in everyday practice.

Goals of CES in health care organizations

Our findings show that the goals of CES in health care organizations are broad and diverse (see fig 3).

Figure 3: Goals of CES



Dutch health care institutions not only aim at fostering accountability and transparency (through policy and protocol work), and developing professionalism (through consultation), but also at stimulating an ethical climate and providing a platform for deliberating on complex situations which emerge daily in contemporary health care practice. The overall aim of CES is defined in terms of enhancing good care.

Chapter 3 shows that, in line with the goal of ‘encouraging an ethical climate,’ Dutch health care institutions aim at spreading CES through the organization. Institutions use various ways to spread CES through the organization, for instance by integrating it with quality policy, identity policy, educational policy, or professional profile.

Goals of health care institutions related to CES can be regarded as elements of larger organizational developments. Thus, the increase of dialogical CES can be seen as a reflection of the growing focus on dialogical organization development, in which the organization is seen as a continuous process of joint meaning making through dialogue, resulting in a dynamic, narrative identity.¹⁰ Encouraging an ethical climate fits to this concept of dialogical organization development as it asks for relational, experiential and narrative knowledge (in addition to evidence based knowledge).

The goal of encouraging an ethical climate and the relationship to dialogical organization development might explain why implicit kinds of CES play an important role in daily practice. Chapter 2, for example, showed that implicit kinds of CES are valued for their natural and narrative approach and contribute to the integration of CES. Open, flexible (non-verbal) communication is a success factor for the integration of CES in the organization.

So, whereas CES was a somewhat isolated staff function in the past, nowadays CES activities are more widely spread in the organization. Health care institutions facilitate inductive, open ended, continuous pathways to organize collective attention for moral reflection.

7.3 Reflections on main findings

In this section we will reflect on our findings on the prevalence and needs and goals of CES in Dutch health care organizations and interpret them, making use of Habermas’ notions of system and life world. This will shed new light on the role of various kinds of CES, planned and unplanned, and monovocal and polyvocal, in Dutch health care.

Habermas¹¹ analyzes the modernization of Western societies as a process of rationalization which has led to a split between the life world, based on communicative action, and systems that are guided by market values and strategic action. The life world is the resource of symbolic representations, personal life experiences and emotions and socio-cultural values like solidarity and fairness. The life world is reproduced in communicative action which is understood as coordinated action with a focus on consensus and mutual understanding. Habermas¹¹ explains that communicative action is fostered by tradition and shared language:

“For members, the life world is a context that cannot be gotten behind and cannot in principle be exhausted. Thus every understanding of a situation can rely on a global pre understanding. Every definition of a situation is an ‘interpretation within the frame of what has already been interpreted, within a reality that is fundamentally and typically familiar.’” (p. 133).

The Dutch philosopher Kunneman¹² compares life world processes with interactions around a ‘camp fire’; life world interactions diffuse light, making visible aspects that are emotionally meaningful for the participants.

In contrast to the life world, the system world is based on institutions and market values, and guided by strategic action, money and hierarchical power. Identities in the system world are mainly reduced to positions and functions; there is no place for the unique person and life story. Kunneman¹² refers to the metaphor of the ‘spotlight’ to characterize the system world; with its concentrated bundle of light it reveals general aspects of the object on which it is focused and puts it in a ‘cold’ light. While life world and system need and complement each other, in modern times the system world has become dominant over the life world. This is called the ‘colonization’ of the life world by the system world.

7.3.1 CES and system world

Our findings about explicit kinds of CES indicate that Dutch health care institutions experience a need for planned CES and that they develop explicit CES, such as ethics committees, to fulfill this need. This is in line with blue print thinking in change management,¹³ focusing on system thinking. From this perspective, change is planned by a small group of people who share ideas and intend to ‘change’ a larger group.² Within the health care domain, system thinking has been developed widely and, for example, provides rationales and frameworks for redesigning health care systems.¹⁴ System thinking focuses on control, and on relationships determined by power and money.¹¹ It brings to light issues that are open to systematic investigations. In line with this, explicit CES may function as a spot light, enabling a structured and well-designed approach to ethical issues.

System thinking implies a specific focus on CES activities and their positioning in the organization. This can be found in CES literature which focuses on organizational mandates, accountability, and underlying causes of behavior with an eye towards changing interactions or redesigning the system to produce different behaviors.^{15, 16} Three leading figures in the field of CES who work in three different countries with different cultures, health care funding structures and settings, developed a top 10 of practices to foster CES.¹⁶ In this list (table 1), various elements of system thinking can be seen. Practices 1, 3, 4, 7, 9, and 10 focus on giving CES a formal position in the organization, and assuring accountability for ethics. The other practices are not necessarily influenced by system thinking, but can easily be accommodated into a system approach.

Table 1: Top 10 practices to foster CES

<ol style="list-style-type: none"> 1) Have a clear organizational mandate 2) Be and stay engaged with the ‘real’ world 3) Take advantage of economies of scale 4) Be practical and useful 5) Be proactive, not reactive 6) Build relationships 7) Maintain a constant improvement orientation 8) Understand key stakeholders 9) Ensure accountability for the ethics program 10) Target root cause organizational factors that influence behavior <p>Mac Rae et. al 2008¹⁶</p>

Our findings about the needs and goals of CES show elements of system thinking. Health care institutions use CES activities for accountability reasons. Having CES is then a way to persuade third parties like the health care insurer and the health inspectorate that (medical-) ethical issues are under control within the organization. Another strategic use of CES we found is its contribution to the identity of the organization and its competitive advantages in relation to other competitors. In these instances CES activities are adopted and adjusted to the values of the market system. CES is thought to be essential for the continuation of the organization.

7.3.2 CES and life world

Although CES can be used for system purposes, health care organizations also have other goals for CES, which cannot be reduced to system values and strategic action. Chapter 4 showed that several respondents regard CES as a reaction to the current culture of control, characterized by management of output and bureaucratic quality assurance procedures. This is in line with previous literature which describes negative consequences of a focus on systems, such as a one-sided attention for mitigating crises instead of paying attention to culture and personality, and emphasizing issues which are manageable in a structured way while keeping people, stories and emotions in the dark.^{11, 17}

Our findings indicate that Dutch health care institutions (both management and professionals) have an eye for kinds of CES which do not fit system-thinking. Respondents stress the importance of deliberations on moral questions which emerge at the coffee machine (as various respondents explained). The emphasis on implicit CES is in line with the concept of life world, which underlines the importance of communicative learning processes, aimed at mutual agreement based on shared language and understanding.¹¹ Several institutions refrain from implementing explicit kinds of CES and indicate that implicit kinds of CES are sufficient to address moral issues (chapter 2). In these institutions, explicit CES innovations are criticized out of aversion to organizational change for the sake of change.

Although the critique of explicit CES is not without grounds, especially in the light of traditional CES in ethics committees, it overlooks that explicit CES is not necessarily dominated by system thinking. Explicit CES can be a way to make life world issues explicit, if there is enough room for communicative action and life world issues. In such cases, explicit CES is not aimed at formulating rules or fixing problems, but at reflection and dialogue grounded in personal experiences and emotions. People with names and faces meet to share, to open up and explore issues that bother them at that particular moment. They create a camp fire situation within the context of the institution with its rules and protocols and pressure to perform. CES then functions as an opening, a space where there is room for what moves people. When experiences and emotions are shared and explored via dialogue, critique of the system world may arise. Our findings (chapter 6) suggest that explicit CES is required to create room for life world issues, since mundane issues do not automatically get the required attention in the daily routines of long term care. CES activities in this context should be of such nature that they tune in with the learning styles of nurses and nurse aids. In other

contexts, more deliberative forms of CES are suitable to increase mutual understanding via communicative action.

Life world processes can be controlled and organized in a systematic way only to a certain extent. Life world processes require internal motivation and commitment, and cannot fully be regulated top-down. Communicative action can be stimulated and fostered by creating good conditions such as sufficient time for participants, and safety. Communicative action may come about within the spaces deliberately created by CES structures if there is room for personal experiences and emotions. CES structures then function as a context in which communicative action can flourish. Our results show that explicit CES does not function well if it is dominated by bureaucratic procedures and rules. In ethical committees, participants need to be motivated internally to remain committed to talk about moral dilemmas. The same is true for MCD; it requires local organization and implementation at team level (chapter 3 and 6), but is not possible without highly motivated individuals who are willing to open up, who dare to be vulnerable and share their experiences and moral dilemmas. This is in line with Kunneman's¹² view on the way life world processes are organized. Around local camp fires, people share stories and emotions, and in the warmth and glow of the fire they interpret their moral dilemmas, what really matters to them, and who they want to be (identity). After the dialogue around the camp fire, important insights on what it means to be a moral person and critique can be fed back to the system world.

7.3.3 CES at the zone of interference between system and life world

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Habermas' concepts of system and life world may help to elucidate the complex position of CES in health care institutions. CES can serve as a tool for controlling ethical issues in line with system thinking. Traditional ways of dealing with ethics through ethical committees and ethical experts show clear signs of this approach. As an antidote, implicit CES is proposed, focusing on life world processes. In order to connect life world and system in a constructive way, forms of CES in which life world experiences are made explicit, and used as input for more general rules and regulations, might be considered promising. Thus, various kinds of CES should be combined in such a way that formal rules do not restrict communicative processes, but are based upon life world interactions and create space for fostering them, and connecting them to system processes. The development of forms of CES which can serve as a bridge between system and life world is not an easy task. Such forms of CES should fit in with the logic of systems (focusing on transparency and accountability), and with the logic of the life world (emphasizing experiential knowledge and dialogue). Implementing MCD as a connection between system and life world requires openness to manage the tensions involved in the attempt to reconcile both schools of thought. Thus, MCD should not be regarded as a definite solution for dealing with ethical issues in current health care, but as a positive attempt to do justice to life world issues in the context of health care organizations which are immersed in system processes. Moreover, creating room for life world experiences and connecting them to system processes in MCD should not be regarded as the task and achievement of ethicists, but as an endeavor which requires joint work between ethicists and practitioners.

7.4 Methodological reflections

In this thesis we adopted a mixed methods way of thinking in which we integrated quantitative and qualitative data. We worked with an open research attitude in which the data guided our research choices. We used a combination of quantitative and qualitative methods, and our interpretation of the data took the form of a back and forth dialog encompassing diverse methods and data sets. Criteria to assess the quality of mixed methods are still under development. We will reflect on our methods, using the questions which were formulated by Mertens¹⁸ (see Chapter 1 of this thesis, and table 2).

Table 2: Questions to assess the quality of mixed methods research

1. What are the multiple purposes & questions that justify the use of a mixed methods design?
2. Has the researcher matched the purposes and questions to appropriate methods?
3. To what extent has the researcher adhered to the criteria that define quality for the quantitative portion of the study?
4. To what extent has the researcher adhered to the criteria that define quality for the qualitative portion of the study?
5. How has the researcher addressed the tensions between potentially conflicting demands of paradigms in the design and implementation of the study?
6. Has the researcher appropriately acknowledged the limitations associated with the data that were collected to supplement the main data collection of the study?
7. How has the researcher integrated the results from the mixed methods? If necessary, how has the researcher explained conflicting findings that resulted from the different methods?
8. What evidence is there that the researcher developed the design responsive to the practical and cultural needs of specific sub groups on the basis of such dimensions as disability, culture, language, reading levels, gender, class and race?

*Table 10.2 Mertens, 2010¹⁸

In response to question 1 and 2, we consider mixed methods justified, since the overall research question also has quantitative as qualitative components. Insight in the ‘state of the art’ requires quantitative data on prevalence, and qualitative data on the importance of various kinds of CES. Understanding the needs for and goals of CES in health care institutions also requires quantitative data (covering the whole range of health care institutions in the Netherlands), and qualitative data (to explain the needs and goals found in the surveys).

In response to question 3 and 4, we adhered to quality criteria of the tradition in which the methods were developed. In our descriptive quantitative approach we maximized the number of respondents by sending two reminders and using expert conversations and pilots to increase reliability and validity (see table). In our descriptive qualitative approach we enhanced the credibility of our findings by sending member checks and triangulating participants and methods.

We aimed at increasing the validity of our survey questionnaires by having expert conversations, pilot testing the questionnaires and sending two reminders to increase the response rate. Our findings might be biased, since managing directors and ethics support staff who responded might be more enthusiastic about CES than non-responders. Yet, we have no indication that respondents gave socially desirable answers. It is also likely that not only people who are enthusiastic about CES responded, since our data included negative experiences with CES. For example, one third of the respondents of SQ 1 responded to the question about the need for CES in the negative. During the research we had some indications that the formulation of questions in SQ 1 might have introduced a bias. Therefore we collected additional qualitative data (interviews and focus groups), to increase our confidence in the data and their interpretation (credibility).

We improved the credibility of our data by triangulation, member check, prolonged and persistent engagement, peer debriefing, purposeful sampling, saturation, constant comparison and search for negative cases. Triangulation implies that we used multiple data sources and methods (e.g. survey questionnaires, interviews and focus groups) and involved more than one person in collecting, analyzing and interpreting data. Member check means that all our interpretations of interviews and focus groups were shared with respondents. Prolonged and persistent engagement implies that we invested sufficient time in data collection activities to ensure an in depth understanding of CES and to focus on the issues which emerged as relevant for CES. We spent more than five years within the CES field and acquired a full picture of CES by including a variety of situations and contexts. Peer debriefing means that we, occasionally, stepped out of the CES context to review perceptions, insights and analysis with professionals outside the context who had enough general understanding of the nature of the study to debrief and provide feedback that refined and redirected the inquiry process. We also enhanced the credibility of our research by purposively selecting the focus group members and interviewees. In our qualitative research, we aimed to do justice to the diversity of the population and therefore we deliberately selected respondents from various contexts and having various kinds of CES. We included interviewees from elderly care, mental health care, care for people with an intellectual disability and hospital care and included institutions with MCD, ethics committees, ethics consultation and implicit CES. We ended the collection of the qualitative data after saturation was reached, and new data did not provide new information. Credibility was also enhanced by constant comparison. We coded the collected qualitative data into emergent themes or codes and constantly revisited the data after initial coding, until no new themes emerged. Finally, we used negative case analysis to warrant the credibility of our research. We purposely sought for data that differed from our expectations, and had an open eye for such data if it appeared spontaneously. For example, we expected that MCD would fit better to the elderly care context than ethics committees, and although this was confirmed in most cases, one case showed that a renewed ethics committee fitted well to the context of elderly care very well. Likewise, we learned from a participant of a focus group that MCD may be considered to be distant from the work floor. From this, we concluded that an interpretation of a specific kind of CES is more important than the method as such.

Reliability is related to the accuracy of the estimation of the prevalence and characteristics of (institutions with) CES, which is achieved by minimizing (systematic and

unsystematic) sources of error.¹⁸ To prevent systematic error we made a clear and (pilot) tested side letter to the questionnaire; to prevent unsystematic error, we did not make changes within SQ 1 (when sending the reminders), although we discovered in the first round that the word ‘service’ in CES has some negative connotations for the respondents.

Dependability is seen as the qualitative parallel to reliability. Whereas reliability refers to stability over time, within the constructivist paradigm, change is expected, but should be tracked and made publicly inspectable.¹⁸ Dependability refers to the absence of a-systematic errors and to the idea that the findings are not dominated by the frames of the researcher.¹⁹ Therefore, the first author kept a diary during the whole research process which gives information about the degree to which results are independent of the propositions of the researcher, time and instruments. Although this diary has not been published, it provided background information which can be consulted and has been consulted while writing the articles and thesis. Dependability also increased by multiple coding. This means that the analysis and interpretation of the data was done by the first author, (co)promoters and three other co-authors. The co-authors were experts for each inference (respectively chapter 2, 3 and 6) and, as they were not actively involved from the start of the research, they were able to look at the data with a ‘fresh set of eyes.’

In response to question 5, we experienced few paradigm tensions. The quantitative data were descriptive, asking for further understanding using qualitative data. This also provides an answer to question 6: we experienced the data from the surveys as limited, and requiring further qualitative data, to better understand answers which respondents gave to questions in the surveys.

Integration of results (question 7) was achieved by comparing the results of quantitative and qualitative methods for each research question and going back and forth between the two. We worked iteratively, and critically reviewed all data available in our study. We repeatedly re-read and re-structured all data separately and as a whole. Within this process we regarded and treated numeric and worded data as equally important. In an active process, we (the primary author and the supervisors) had dialogues about the value of the qualitative and quantitative data for each inference (presented in the previous chapters). This was a continuous process which already started with the question: should we start with quantitative or qualitative methods? The exploratory literature review helped in answering this question and resulted in a start with survey questionnaire 1. During the analysis of the data, we continuously asked ourselves: what do the numeric findings mean, and we collected qualitative data to deepen and broaden our understanding. The interviews and focus groups sometimes challenged our quantitative findings; we specifically reflected on such tensions between different kinds of data. Finally, data of all types were assembled and the question about the value of each finding and method was addressed also within the writing phase. So, data of multiple and diverse kinds strengthen our inference quality, and as we used an integrative design, the question about the value of each finding and method returned within all research phases.

In response to question 8, we did not specifically look into vulnerable sub groups. Our focus was on the views of managing directors and ethics support staff, not on the experiences of marginalized groups. Yet, we did put the needs of less powerful groups on the agenda, for instance in the chapter on elderly care.

Strengths and limitations

The strengths of this thesis are the broad scope, the open research approach, the methodological variety, and the introduction of the perspectives of managing directors and ethics support staff to further the understanding of CES.

The thesis has a broad scope in that it provides an overview of CES in the Netherlands, including various kinds of CES (in addition to ethics committees and ethics consultants, also MCD and implicit ethics support), and various contexts (hospitals, mental health care, care for disabled people and elderly care). Such an overview was missing until now. It can serve as base for international comparison and further development of CES.

The open research approach we used provided opportunities to deal with difficulties along the research path and provided a base to present new insights for the field of CES. We, for example, contributed to the theoretical base of CES by introducing the notion of implicit kinds of CES. Implicit CES refers to situations in which ethics support is not formally and structurally organized and ethical issues are not explicitly put on the agenda. While ethicists may tend to regard conversations about ethical aspects of care as explicit CES (assuming that professionals explicitly talk about moral issues), our research indicates that many conversations between practitioners (for example between a nurse and a middle manager) relate to ethical issues which are not explicitly expressed as such. Moral questions emerging in regular (work) meetings, for example, are not made explicit nor facilitated by using an ethics method or formal ethical expertise.

Until now these conversations lacked specific attention within CES literature (some articles about ethical climate may be considered to allude to it, but the extent seems to be marginal) and we could only deepen our findings on this as a consequence of the open research approach.

The fact that this was one of the first mixed methods studies investigating CES adds significantly to the relevance of the thesis. In contrast to previous (Dutch as well as international) research we used various research methods to get insight into practices and policies concerning ethical issues in health care institutions. Combining quantitative and qualitative methods in clinical ethics is useful at a time when the absence of strong evidence is hindering progress in CES. The methodological variety of this thesis is reflected in the use of different methodologies in the various chapters, which permitted triangulation of the research findings. In all chapters we combined qualitative and quantitative methods and focused on the perspectives of top management and ethics support staff concerning CES.

Concerning the latter, the introduction of the perspectives of managing directors and ethics support staff working in health care practice, to further understanding of CES, is a third strength of this thesis. Most CES literature focuses on the views and experiences of ethicists. The perspective of those who make policy decisions in health care institutions and organize CES in daily practice is missing. This thesis therefore fills a gap in the CES literature.

The limitations of this study concern its generalizability, international variety as potential danger for the validity of survey questionnaire 1, the inclusion of only two stakeholder perspectives, and a limited transformative impact.

The generalizability of the quantitative results can be questioned, because respondents of the questionnaires might not be a representative group. In the first survey questionnaire,

which also provided the names of the respondents of survey questionnaire 2, we addressed all Dutch health care institutions. A potential source of bias is that the respondents of the survey questionnaires might be more interested in CES than non-respondents. Therefore caution is needed in claiming that the findings will hold for non-responding health care institutions or for health care institutions outside of the Netherlands.

A further danger for the validity of the research is the question of to what extent the definitions of CES we have used correspond with the interpretations of respondents of the survey questionnaires. A first problem in this respect is that we used an international questionnaire as basis for our first questionnaire. We decided to do this for reasons of comparability, although we realized that the Dutch context might differ from the international scene. In the questionnaires, we referred to definitions of CES found in the literature. This implies a potential problem for the validity of the research. Did respondents have the same concept in mind as described in the (international) literature? It might be possible that respondents report a specific kind of CES, for example MCD, being present, without being aware of the exact definition. This might have resulted in over-reporting. Although this cannot be fully excluded, we have tried to prevent this, by providing our definition of various kinds of CES in the questionnaires, and specifically asking the respondents whether the definition which is provided, is used in the same way in their institution. A further problem concerns the definition of forms of CES which emerged in our research. In questionnaire 1, we asked in an open question whether respondents could mention other kinds of CES prevalent in their institution. The answers to this question provided us with kinds of CES which we had not anticipated. We used the term 'implicit CES' to denote these CES activities. One may wonder whether our definition of implicit CES was clear enough for the respondents of questionnaire 2 to ensure that the answers they gave about prevalence are correct.

A further weakness is that we only investigated the views and experiences of two stakeholder groups: managing directors and ethics support staff. Other relevant groups, such as professionals, patients and family were not addressed.

Finally, the transformative impact of our study is limited. Given our descriptive research goals, we did not contribute to the further development of CES in the Netherlands. Although we formulated recommendations for practice, for instance regarding the combination of explicit and implicit CES, and the requirement of accommodating CES activities to the specific needs of health care settings, our research did not entail empowerment and emancipation of groups involved in developing CES in health care institutions, which would have strengthened the societal impact of the research.

7.5 Implications for future research on CES

In this paragraph we describe the implications for future research on CES.

Implicit CES

Our findings suggest that implicit CES is highly prevalent in Dutch health care institutions, and that it is valued because it fosters attention for the ethical dimension of care in an organic way. Additional research on various kinds of implicit kinds of CES, and how they work is needed. In this research, the quality of implicit CES should also be addressed.

Relationship between implicit and explicit CES

Our research indicated that combining implicit and explicit CES might contribute to embedding ethics integrally into the organization. Follow up research is required to investigate the relationship between explicit and implicit CES, and the tasks and roles of clinical ethicists. We also recommend research into MCD as a potential bridge between implicit and explicit CES. What would this mean for the position of MCD in the organization? Does the attempt to rationalize implicit forms of deliberation result in an approach which does justice to the logic of both system and life world?

Needs for CES from various perspectives

This study was conducted among respondents in the higher echelons of care institutions. We recommend to investigate the needs for ethics support from the perspectives of care providers (including physicians, nurses and other professionals) and recipients of care (patients and families). Likewise, it would be appropriate to get more insight into the needs for ethics support envisaged by parties outside the institution, such as national policy makers, health care insurance companies and professional and patient organizations.

Outcomes of various kinds of CES

Future research on the outcomes of various kinds of CES (and their relation) is required, in order to see whether the effects of CES are in line with the needs for and goals of CES in health care institutions, identified in this thesis. Additional research should include instruments to assess the outcomes of implicit and explicit CES, both from a system perspective, and taking life world aspects of CES into account.

7.6 Implications for CES practice

Combine implicit and explicit CES

We recommend combining implicit and explicit CES in order to build on the moral insights of participants, adapt CES to the learning styles of participants and focus on joint moral learning in practice. After formal education has been completed, learning should realistically be continued. Work-based learning is probably a good way to do this. Moral case deliberation may stimulate moral reflection of practitioners on concrete experiences of moral dilemmas. Another example of CES grounded in concrete experience is the sTimul care ethics lab. This is an educational setting where nurses take the role of a patient in order to experience what it means to be a care-receiver.

Recognize the variety of needs for and goals of CES

We recommend that proponents of CES take into account needs and goals in health care organizations and accommodate CES in the organizational setting, to foster its use and implementation. The model developed in chapter 5, distinguishing various goals of CES,

can be used as a tool in dialogues about goals between various participants in health care institutions. Creating a fit between underlying values of CES and organizational culture will foster the acceptance of CES within organizations and add to the effectiveness of CES. This should not be organized by ethics support staff only; the choice for intermediate goals fitted to the organization is ideally the outcome of a dialogue between the top of the health care institutions, advocates of CES and practitioners, as this fosters commitment for CES.

Involve all stakeholder groups in CES

Our results suggest that a heterogeneous composition of CES in which managers, health professionals and patients and their families all actively participate contributes to the development of CES. Therefore it is important to connect CES to the (changing) needs of various stakeholders. This requires CES facilitators who are able to connect to various stakeholder groups and their ethical issues. It also requires CES methods in which there is focus on various perspectives and ethical issues. Hence, we recommend using CES methods which consider and value the differences between various perspectives and are able to foster communication between the various parties.

Pay attention to ethical climate in developing CES

In chapter 5 we showed that institutions not only aim at ethical policy, protocols and case consultation, but also at developing an ethical climate. CES activities and structures should be developed, in line with these goals. Therefore we recommend organizing CES focusing on ethical climate, reflection-in-action, openness and dialogue. Ethically sensitive educated professionals may act as role models and foster cultural change in the workplace, if supported by leadership from top and middle management. Middle managers in particular might serve as role models and create the opportunity and space for reflection. We recommend that ethical competence become part of the criteria for recruiting professionals and middle managers.

REFERENCES

1. Van Dartel JN van, Jacobs M, Jeurissen RJM. *Ethiek bedrijven in de zorg. Een zaak van het management*. 2002 Gorcum bv, Assen.
2. Homan T. *De binnenkant van organisatieverandering*. 2008 Kluwer, Alphen aan den Rijn
3. Ohnsorge K, Widdershoven G. Monological versus dialogical consciousness- two epistemological views on the use of theory in clinical ethical practice. *Bioethics* 2011; 25 (7): 361 – 369.
4. Aulasio M, Arnold RM, Youngner SJ. *Ethics consultation from theory to practice*. 2003. John Hopkins University press.
5. Molewijk AC, Abma T, Stolper M, Widdershoven G. Teaching ethics in the clinic. The theory and practice of moral case deliberation. *J Med Ethics*. 2008 Feb;34(2):120-4.
6. Rudnick A. The Ground of Dialogical Bioethics. *Health Care Analysis* 2002, 10: 391–402
7. Abma TA, Widdershoven GAM, Frederiks BJM, van Hooren RH, van Wijmen F, Curfs PLMG. Dialogical Nursing Ethics: the Quality of Freedom Restrictions. *Nurs Ethics* 2008 15 (6): 789-802
8. Van der Dam. *Ethics support in elderly care. Developments and specific needs for ethics support, and an evaluation of moral case deliberation in two Dutch elderly care organizations*. 2012. University Press Maastricht.
9. Svantesson M, Lofmark R, Thorsen H. et al. Learning a way through ethical problems: Swedish nurses' and doctors' experiences from one model of ethics rounds. *J Med Ethics* 2008; 34: 399–406.
10. Wijsbek L. *De dialogische organisatie*. 2009. Van Gorcum.
11. Habermas J. *The theory of communicative action. A critique of functionalistic reason*. (T. McCarthy, Trans. Vol 2:lifeworld and system). London: Polity Press, 1987.
12. Kunneman H. Presentation. 2009. Openingslezing symposium reflectie in de zorg. Week van de reflectie. This presentation is published at: www.human.nl
13. Caluwé, L. de & Vermaak, H. (2003). *Learning to change. A guide for organization change managers*. Thousand Oaks: Sage Publications.
14. Berwick D. A User's Manual For The IOM's 'Quality Chasm' Report. Patients' experiences should be the fundamental source of the definition of "quality." *Health Affairs* 2002, 21 (3): 80-90
15. Silverman HJ. Organizational ethics in health care organizations: pro-actively managing the ethical climate to ensure organizational integrity. *Hec Forum*, 2000; 12 (3): 202-215
16. Mac Rae SK, Fox E, Slowther A. Clinical ethics and system thinking. In: *the Cambridge textbook of bioethics*. Ch. 40: 313-321
17. Abma T, Dauwerse L, van der Borg W, Verdonk P. *De herontdekking van de zorg. Het belang van vertrouwen, ruimte en verbinding in de ouderenzorg*. 2011. Eindrapport evaluatie Van Harnas Naar Zomerjerk.
18. Mertens, D. M. (2010). *Research and evaluation in education and psychology. Integrating diversity with quantitative, qualitative and mixed methods*. Washington DC: Sage publications
19. Baur V. *Participation and partnership. Developing the influence of older people in residential care homes*. Box press 's Hertogenbosch, 2012.

SUMMARY

During recent decades, attention on clinical ethics has increased in the Netherlands. New kinds of ethics support like moral case deliberation (MCD) have been introduced. The growing attention on and implementation of different kinds of clinical ethics support (CES) gives rise to various questions. What kind of CES is available in health care institutions? What kind of CES is needed for dealing with current ethical issues in health care? In this thesis we will address these questions, focusing on the Dutch context.

The aims of the study were to provide an overview of: 1) the prevalence and characteristics of CES in the Netherlands, and 2) the goals and needs of CES from the perspective of top managers and ethics support staff of health care institutions. The central research question was: what is the state of the art of CES in the Netherlands? The sub questions were:

1. How prevalent is CES and what are its characteristics in the Netherlands?
2. What are the needs and goals of CES in Dutch health care institutions?

This thesis consists of two parts. Part 1 focuses on the prevalence of CES in the Netherlands; part 2 describes the needs and goals of Dutch health care institution in relation to CES.

Chapter 1 provides an introduction to the research questions of the thesis. It describes the increased interest in CES, against the background of new developments in health care. In health care, the patient population has become more fragile, and more active and critical at the same time; health care professionals have got more possibilities of treatment and care as a consequence of the increase of medical knowledge, and increasingly have to cooperate in interdisciplinary teams; organization of health care has become more bureaucratic and formal, but is also increasingly confronted with moral challenges which cannot be solved by using formal approaches only.

The chapter also provides a short explanation of various notions in ethics. It describes how applied ethics implied a move from ethical theory to ethical issues in practice. It also touches upon the notion of bioethics, as an interdisciplinary academic field and public movement which crosses traditional academic boundaries. Furthermore, it introduces the concepts of clinical ethics and clinical ethics support.

This chapter also describes previous survey studies on CES in the USA, Canada and Europe (focusing specifically on the Netherlands). Most surveys describe the use of clinical ethics committees or ethics consultants as the main kind of CES. MCD, which has increasingly been receiving attention in the Netherlands, is not addressed in existing surveys. Furthermore, within the existing surveys, little attention has been paid to what management of health care institutions sees as needs and goals of CES.

Part 1 Prevalence and characteristics of CES in the Netherlands

Chapter 2 describes the prevalence of explicit and implicit kinds of CES in Dutch health care institutions, including hospital care, mental health care, elderly care and care for people

with an intellectual disability. In explicit CES, the ethical dimension of care is structurally and professionally addressed; in implicit CES, ethical issues are handled indirectly and in an organic way. The findings demonstrate that the presence of ethics committees is relatively high in the Netherlands, especially in hospitals. Moral case deliberation is present in about half of all Dutch health care institutions and in two thirds of the mental health care institutions. Ethics consultants are not very prominent. Our findings indicate that explicit CES is often combined with implicit forms of CES, and that MCD might be a bridge between the two.

Chapter 3 focuses on the prevalence and characteristics of MCD in various settings of Dutch health care. The findings demonstrate that the prevalence of MCD is relatively high in Dutch health care (44% have MCD), especially in mental health care (in which MCD is reported as present in the organization by 62% of the respondents).

Institutions with MCD differ from institutions without MCD concerning size, kind of problems and importance of ideological background. Characteristics of MCD include that it is often carried out for 3 years or more, has a high participation of health professionals and middle managers and is both organized scheduled as unscheduled. In relation to the positioning of MCD, another significant issue is integration in existing policy of key persons as they emerge. We conclude that MCD is a part of an integrated ethics policy and serves as a (bottom up) catalyst for such an integrated ethics policy.

Part 2 Needs and goals of CES in Dutch health care institutions

In *chapter 4*, we investigate the need for CES from the perspective of managing directors and ethics support staff to understand which factors are relevant in explaining the presence or absence of such need in health care institutions. This chapter provides an evaluation of the need for CES in Dutch health care and the potential barriers to its development. It shows that the need for CES is not a given and aversion to innovation, negative associations with the notion of ethics support service, and organizational factors, such as resources and setting, limit the considered need for CES. Our findings show that most respondents see a need for ethics support and this is related to the complexity of contemporary health care, the contribution of ethics support to the core business of the organization and to the added value of paying structural attention to ethical issues. The promotion of CES in health care can be fostered by focusing on formats which fit the needs of (practitioners in) health care institutions. The emphasis should be on creating a (culture of) dialogue about complex situations which emerge daily in contemporary health care practice.

Chapter 5 describes the goals of CES as perceived by managing directors and ethics support staff. Four main clusters of goals were found: 1) encouraging an ethical climate; 2) fostering an accountable and transparent organization; 3) developing professionalism; and, overarching the previous three, 4) good care. Important sub-goals of ethics support were: attention for ethical issues; raising awareness of ethical issues; fostering ethical reflection and supporting employees. The chapter ends with a discussion on the desirability to further operationalize the general goal of good care, the context-boundedness of our findings and

the need to relate goals of ethics support to the features of organizational cultures to further improve the integration of ethics support in health care institutions.

Chapter 6 describes the development of CES in elderly care. Our findings suggest that this setting (and possibly in long term care as a whole) shows specific needs in relation to CES. The data indicate that advice-based forms of CES transcend and do not match up with the nature of moral problems found in elderly care. Advice-based forms of ethics support are far removed from actual practice and not in tune with real issues in the workplace. Many moral issues in elderly care arise daily, and often involve seemingly ‘trivial’ issues. Therefore, CES should (according to our respondents) first and foremost help health professionals recognize and identify these problems as being moral problems.

Our respondents indicate that specific needs for ethics support are also related to the educational level of health professionals, and they draw attention to feelings of powerlessness as a human response to the chasm between their low educational level and the complex questions they encounter. Instead of being acknowledged for the difficult work they do, nurses are overloaded with new assignments and innovations which may, in turn, further increase their feeling of powerlessness. There is a need for empowerment rather than for just ethics support.

Chapter 7 provides a discussion of the outcomes of the thesis. It first summarizes the main findings. Then, Habermas’ notions of system and life world are used to reflect on the findings, and clarify why various kinds of CES are present in the Netherlands and how they are appreciated by managing directors and ethics support staff in health care institutions. Next, the chapter contains a reflection on the methods used, and elaborates on their strengths and weaknesses. Finally, recommendations for research and practice are formulated.

SAMENVATTING

Sinds een aantal decennia neemt de aandacht voor klinische ethiek in Nederland toe. Er worden nieuwe vormen van ethiekondersteuning zoals moreel beraad (MB) geïntroduceerd. Deze groeiende aandacht voor en implementatie van verschillende soorten ethiekondersteuning leidt tot diverse vragen. Welk soort ethiekondersteuning is aanwezig in zorginstellingen? Welk soort ethiekondersteuning is nodig om het hoofd te bieden aan hedendaagse ethische problemen? In dit proefschrift zullen we ingaan op deze vragen, gericht op de Nederlandse context.

De doelen van de studie zijn: 1) een overzicht geven van de prevalentie en karakteristieken van klinisch ethische ondersteuning (CES) in Nederland en 2) een overzicht geven van de behoeften aan en doelen van CES vanuit het perspectief van bestuurders van zorginstellingen en medewerkers verantwoordelijk voor de organisatie van ethiekondersteuning.

De centrale onderzoeksvraag is: wat is de stand van zaken rond CES in Nederland? De sub vragen zijn: 1) Wat is de prevalentie en wat zijn de karakteristieken van CES in Nederland? 2) Wat zijn de behoeften en doelen van CES in Nederlandse zorginstellingen?

Dit proefschrift bestaat uit twee delen. Deel 1 is gericht op de prevalentie en karakteristieken van CES in Nederland; deel 2 beschrijft de behoeften en doelen van Nederlandse zorginstellingen in relatie tot CES.

Hoofdstuk 1 geeft een introductie bij de onderzoeksvragen van dit proefschrift. Het beschrijft de toegenomen interesse in CES tegen een achtergrond van nieuwe ontwikkelingen in de zorg. In de zorg is de patiëntenpopulatie kwetsbaarder geworden en tegelijkertijd actiever en kritischer; professionele zorgverleners hebben meer behandelmogelijkheden gekregen als een gevolg van de toegenomen medische kennis en moeten steeds vaker samenwerken in interdisciplinaire teams; de organisatie van zorg is bureaucratischer en formeler geworden, maar wordt ook in toenemende mate geconfronteerd met morele uitdagingen die niet kunnen worden opgelost door een formele aanpak.

Dit hoofdstuk geeft ook een korte uitleg bij de verschillende begrippen in de ethiek. Het beschrijft hoe toegepaste ethiek een beweging in gang zette van ethische theorie naar ethische onderwerpen in de praktijk. Dit hoofdstuk beschrijft ook het begrip bio-ethiek als een interdisciplinair academisch veld en publieke beweging die traditionele academische grenzen overschrijdt. Verder introduceert het de concepten klinische ethiek en klinisch ethische ondersteuning (CES).

Het hoofdstuk geeft een overzicht van eerdere survey onderzoeken naar CES in de Verenigde Staten, Canada en Europa (met een specifieke focus op Nederland). De meeste survey onderzoeken gaan in op ethische commissies of ethische consultants als belangrijkste vorm van ethische ondersteuning. MB, dat in toenemende mate aandacht krijgt in Nederland, is nog niet beschreven in bestaand survey onderzoek. Ook impliciete vormen van ethiekondersteuning, zoals (multidisciplinair) werkoverleg en (ad hoc) overleg met specifieke individuen die ondersteuning bieden zijn tot dusverre niet belicht. Ten slotte is er

in bestaande surveys weinig aandacht voor de visie van het management van zorginstellingen op behoeften en doelen van CES.

Deel 1 Prevalentie en karakteristieken van CES in Nederland

Hoofdstuk 2 beschrijft de prevalentie van expliciete en impliciete CES vormen in Nederlandse zorginstellingen, te weten ziekenhuizen, geestelijke gezondheidszorg, ouderenzorg en zorg voor mensen met een verstandelijke beperking. In expliciete CES is er structurele en professionele aandacht voor de ethische dimensie van zorg; in impliciete CES wordt op een indirecte en organische manier omgegaan met ethische onderwerpen. De bevindingen laten zien dat de aanwezigheid van ethische commissies relatief hoog is in Nederland, vooral in ziekenhuizen. Moreel beraad (MB) is aanwezig in ongeveer de helft van alle Nederlandse zorginstellingen en in twee derde van de instellingen voor geestelijke gezondheidszorg. Ethische consultatie is niet vaak aanwezig in Nederland. Onze bevindingen laten zien dat expliciete CES vaak gecombineerd wordt met impliciete vormen van CES en dat moreel beraad een brugfunctie tussen beide zou kunnen spelen.

Hoofdstuk 3 is gericht op de prevalentie en karakteristieken van MB in verschillende sectoren. De bevindingen laten zien dat de prevalentie van MB relatief hoog is in Nederlandse zorginstellingen (44% heeft MB), vooral in de geestelijke gezondheidszorg (waar MB als aanwezig in de organisatie wordt genoemd door 62% van de respondenten). Instellingen met MB verschillen van instellingen zonder MB in grootte, type problemen en belang van ideologische achtergrond. Karakteristiek voor MB is dat het vaak meerdere jaren bestaat, dat de deelnemers meerdere disciplinaire achtergronden hebben en dat het zowel systematisch als ad hoc plaatsvindt. Integratie in bestaand beleid en sleutelfiguren als ambassadeurs bevorderen de positionering van MB. We concluderen dat MB deel dient uit te maken van een geïntegreerd ethiekbeleid en als een (bottom up) katalysator kan dienen voor een geïntegreerd ethiekbeleid.

Deel 2 Behoeften en doelen van CES in Nederlandse zorginstellingen

In *Hoofdstuk 4* onderzoeken we de behoefte aan CES vanuit het perspectief van bestuurders en ethiekmedewerkers en potentiële barrières voor de ontwikkeling van CES in zorginstellingen. Het hoofdstuk laat zien dat de behoefte aan CES geen gegeven is; aversie ten opzichte van innovaties, negatieve associaties met het begrip ethische ondersteuningsdiensten en organisatorische factoren zoals bronnen en sector, beperken de behoefte aan CES. Onze bevindingen laten zien dat de meeste respondenten van mening zijn dat hun instelling behoefte heeft aan ethische ondersteuning. Dit hangt samen met de complexiteit van de hedendaagse gezondheidszorg, de bijdrage van ethiekondersteuning aan de kerntaken van de organisatie en de ervaren meerwaarde van het besteden van aandacht aan ethische onderwerpen. De ontwikkeling van CES in de zorg kan bevorderd worden door aan te sluiten bij de behoeftes van (beroepskrachten in) zorginstellingen en door het creëren van (een cultuur van) dialoog over complexe situaties die zich dagelijks voordoen in de hedendaagse zorgpraktijk.

Hoofdstuk 5 beschrijft de doelen van CES zoals bestuurders en ethiekmedewerkers die ervaren. Er worden vier hoofdclusters van doelen onderscheiden: 1) bevorderen van een ethisch klimaat, 2) voeden van een verantwoordelijke en transparante organisatie, 3) ontwikkelen van professionaliteit en, overkoepelend ten opzichte van de vorige drie, 4) goede zorg. Belangrijke sub doelen van ethiekondersteuning zijn: aandacht voor ethische onderwerpen, het bewustzijn ten opzicht van ethische onderwerpen verhogen, ethische reflectie bevorderen en werknemers ondersteunen. Dit hoofdstuk eindigt met een discussie over 1) de wenselijkheid om goede zorg als doel verder te operationaliseren, 2) de noodzaak om de bevindingen in de juiste context plaatsen en 3) de behoefte om de doelen van CES te verbinden met de specifieke kenmerken van een organisatie zodat de integratie van CES in die zorginstelling wordt bevorderd.

Hoofdstuk 6 beschrijft de ontwikkeling van CES in de ouderenzorg. Onze bevindingen suggereren dat deze sector (en mogelijk langdurige zorg in zijn geheel) specifieke behoeften heeft in relatie tot CES. De data wijzen erop dat advies gerichte vormen van CES voorbij gaan aan en niet passen bij de aard van morele problemen in de ouderenzorg. Advies gerichte vormen van ethische ondersteuning zijn ver verwijderd van de actuele praktijk en niet in overeenstemming met de onderwerpen die leven op de werkvloer. Veel morele onderwerpen in de ouderenzorg dienen zich dagelijks aan en lijken triviaal. Daarom zou CES professionals moeten helpen om deze problemen als morele problemen te (h)erkennen en identificeren. Onze respondenten geven aan dat specifieke behoeften aan CES ook gerelateerd zijn aan het opleidingsniveau van professionele zorgverleners. Zij wijzen op gevoelens van machteloosheid ten gevolge van het gat tussen het lage opleidingsniveau en de complexe ethische vragen in de praktijk. In plaats van erkenning voor het moeilijke werk dat zij doen, worden verpleegkundigen en verzorgenden overspoeld met nieuwe opdrachten en innovaties die, op hun beurt, de gevoelens van machteloosheid vergroten. Er is meer behoefte aan empowerment dan alleen aan CES.

Hoofdstuk 7 bediscussieert de uitkomsten van het proefschrift. Allereerst wordt een samenvatting gegeven van de belangrijkste bevindingen. Vervolgens worden Habermas' noties van systeem en leefwereld gebruikt om te reflecteren op de bevindingen en om te verhelderen waarom verschillende CES vormen in Nederland aanwezig zijn en hoe ze gewaardeerd worden door bestuurders en ethiekmedewerkers in zorginstellingen. Ook bevat het hoofdstuk een reflectie op de gebruikte methoden en op de sterktes en zwaktes daarvan. Tot slot worden aanbevelingen voor onderzoek en praktijk geformuleerd.

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CURRICULUM VITAE

Linda Marie-Jose Dauwerse was born on December 3, 1980 in Heerlen, the Netherlands. She completed secondary school (Atheneum) at the Trevianum Scholengroep Sittard (2000). In the same year she started her study Health Sciences at Maastricht University. After successfully completing her first year of Health Sciences, she transferred to HBO-V (bachelor), worked as nursing assistant in home care and graduated as a registered nurse (level 5) in 2005. Then she worked for 1,5 year as a psychiatric nurse at an open department for people with autism spectrum disorder in Venray and at a psychiatric department at a general hospital in Nijmegen. Between 2006 and 2007 she finished the Master Care Sciences (Health Sciences). During this master she fulfilled her internship at the department Health, Ethics and Society at Maastricht University, resulting in her master thesis. After graduating, Linda started working as a PhD student at the department Health, Ethics and Society at Maastricht University (CAPHRI) resulting in this thesis working for the department of metamedica (EMGO) at VUmc. Her PhD trajectory revolved around clinical ethics support (CES) and aimed at gaining insight in the current provision and characteristics of various kinds of CES and investigated the needs and goals of health care institutions regarding CES, given the changes in health care. During this period she also completed three responsive research projects. The first two were transformative responsive research projects aiming at giving a voice to 1) people with acquired brain injury and 2) people with Parkinson's disease. The third responsive research project was an evaluation which evaluated transitions initiated by a change project in three elderly care institutions. Currently she works at the Fontys University of Applied Sciences, School of Nursing in Eindhoven.



Linda is happily married to Martijn Boermans and is mother of two daughter. Beyond her work she enjoys cycling, running and swimming.

OVERIGE PUBLICATIES

Dauwerse L, Hendriks A, Schipper K, Struiksma C, Abma T. Quality of Life of Patients with Parkinson's Disease. 2013. Accepted for publication in Brain Injury.

Dauwerse, L., Hendriks, A., Moosdijk van de L., Leedekerken, W., Dellebeke, H., Tulp, H., Hoofd van het M., Schipper K., Abma, T. (2012). Bewogen door onderzoek. De stem van mensen met de ziekte van Parkinson over kwaliteit van leven en onderzoeksagendering. Eindrapport.

Abma, T., Dauwerse, L., Van der Borg, W., Verdonk, P. (2012). De Herontdekking van de Zorg. Het belang van vertrouwen, ruimte en verbinding in de ouderenzorg. Responsieve evaluatie van transitieprogramma 'Van Harnas naar Zomerjurk.' Eindrapport.

Dauwerse, L. (2010). H 7: Behoeftte aan ethische ondersteuning bij vragen naar goede zorg? In: Reflectie en participatie in zorg. Boom / Lemma.

Dauwerse, L., Abma, T., Wolbers, J. (2010). "The war in my head." BMJ patient journey. 26;340

Landeweer E., Abma T, Dauwerse L, Widdershoven G. (2010). Triad collaboration in psychiatry. Privacy and confidentiality revisited. IJFAB. Special Issue: Feminist perspectives on ethics in psychiatry.

Schipper K, Visser-Meily A, Hendriks A, Dauwerse L, Willems V, Hindriks H, Hosli E, Abma T. 'Hersenletsel is 24 uur per dag werken.' Over maatschappelijke participatie van mensen met hersenletsel. Revalidata 2010; 158:13-15.

Hendriks A., Schipper K., Dauwerse L, Willems V, Hindriks H, Hosli E, Abma, T. (2010). Participeren met hersenletsel in de maatschappij anno 2010. Een samenspel van krachten. Medische antropologie 2010; 22 (2):339-360.

Willems V., Dauwerse L., Hendriks A., Schipper K., Abma, T. (2010). Re-integratie na een niet- aangeboren hersenletsel: een kwestie van vallen en opstaan. Attent 24;3; 26-27

Schipper K, Hendriks A, Dauwerse L, Willems V, Abma T. 2010. Deelnemen, geven en zijn. Eindrapportage Sociaal Maatschappelijke Participatie van mensen met niet-aangeboren hersenletsel vanuit patiënten perspectief.

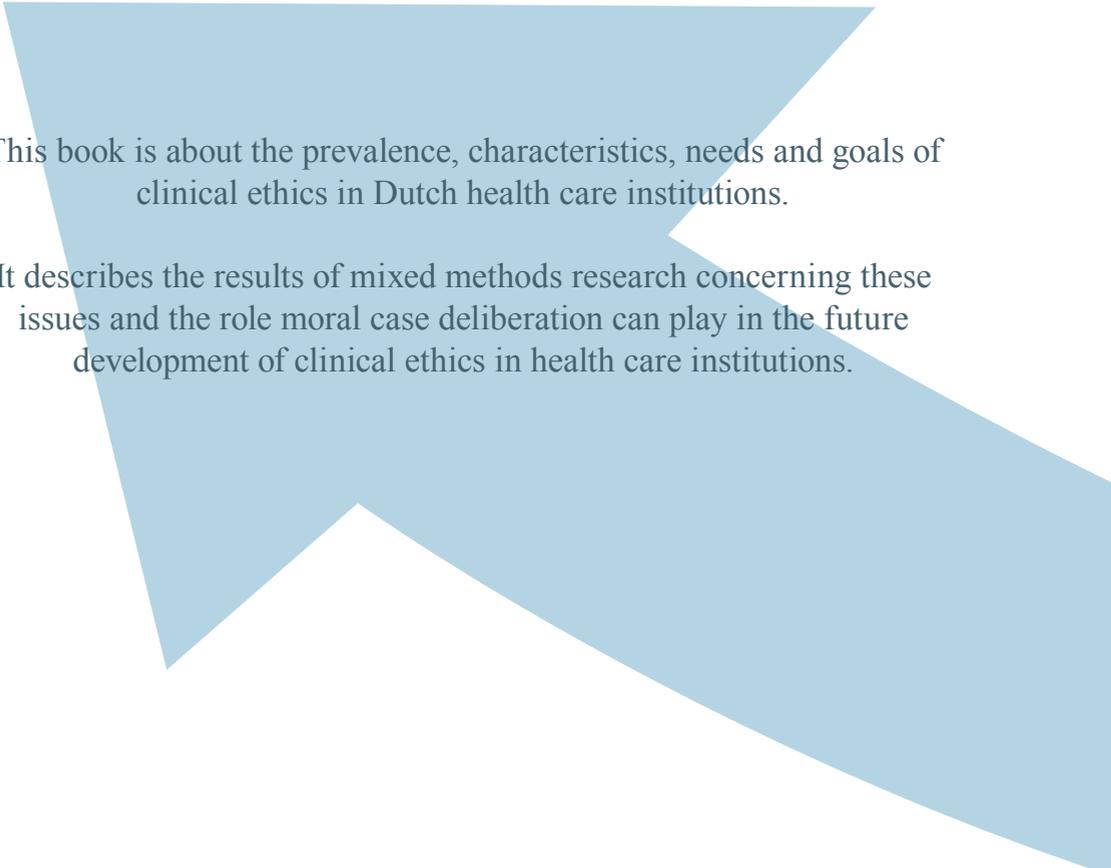
Bles van der W. (2010). Dilemma's in de zorg van dichtbij. Gesprek met Linda Dauwerse over CES in Nederland. Trouw, De Verdieping.

Landeweer, E., Dauwese L., Abma, T., Wilmes, R., Widdershoven, G. (2009). Antwoord op “Autonomie en emotionele zelfstandigheid niet verwarren,” De Pater, M., Van den Brink, T. Het maandblad in de zomer, *MGI*, 7/8 (64): 621-622.

Dauwese L., Abma T., Landeweer E, Wilmes R., Emmaneel R, Widdershoven, G. (2009). “Familie betrekken bij dwang(reductie): altijd wenselijk?” *MGV* 64 (1/2), 5 - 7.

Steinkamp, N., Dauwese L. “Je moet het durven om iets te zeggen, je moet het lef hebben om toe te geven dat je vragen hebt.” (2008). Gesprek met Norbert Steinkamp over de Nijmeegse methode van moreel beraad. Interview door Linda Dauwese. *TGE* 18 (2), 50 - 52.

Dauwese, L., Molewijk B., VWS stimuleert promotieonderzoek. *TVZ*, dec. 2008



This book is about the prevalence, characteristics, needs and goals of clinical ethics in Dutch health care institutions.

It describes the results of mixed methods research concerning these issues and the role moral case deliberation can play in the future development of clinical ethics in health care institutions.

MOVING ETHICS